Chapter 3
Tracking, Reporting, & Follow-Up

Randi Winston-Gerson, AuD, CCC-A; & Jeff Hoffman, MS, CCC-A

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Purpose of Tracking, Reporting, and Follow-Up

Screening alone cannot assure a child with a hearing loss will be identified. Babies not passing the inpatient hospital screen will often need to go through a follow-up process consisting of a series of services and handoffs involving multiple providers. Families going through this process are often challenged with complicating factors and barriers preventing the provision of timely services. State programs have tracking and surveillance systems in place to drive their follow-up efforts and help connect families—in accordance with the Centers for Disease Control and Prevention (CDC) EHDI national 1-3-6 goals:

- Screen no later than 1 month of age.
- Diagnose no later than 3 months.
- Enroll in early intervention programs no later than 6 months (CDC, 2003).

In order to meet these goals in an efficient and timely manner, a coordinated effort consisting of tracking, reporting, and follow-up must occur. This is normally led by the EHDI follow-up program within the state public health department, where a secure and comprehensive centralized database is housed. Depending on an individual state's specific reporting requirements, data is reported to the state EHDI program on an ongoing basis from hospital screening programs, audiologists, early intervention programs, medical home providers, and family support programs. This allows the state EHDI follow-up program to account for and provide individualized case management and follow-up on babies going through the process. A robust data management system is integral to a state's ability to successfully orchestrate the time-sensitive follow-up activities needed to ensure a child gets from screening to diagnosis and into early intervention.

In addition to the utilization of data for tracking and follow-up efforts, EHDI programs can utilize data to drive program evaluation efforts. Programs must have ongoing checks and balances in place to ensure that EHDI goals and outcomes are being attained, that entities providing follow-up services are monitored, and the degree to which established benchmarks are being met.

NCHAM National Center for Hearing Assessment and Management Utah State University™

Public Health Perspectives

Healthy People 2020. Newborn hearing screening (NHS) and follow-up services are included in Healthy People 2020—the nation's current comprehensive health promotion and disease prevention agenda. Objective ENT-VSL-1 of Healthy People 2020 seeks to "increase the proportion of newborns who are screened for hearing loss by no later than age 1 month, have audiologic evaluation no later than age 3 months, and are enrolled in appropriate intervention services by no later than age 6 months" (U.S. Department of Health and Human Services, 2011). The targeted percentage for each objective was set as a 10% improvement over the baseline percentages in 2007. The Healthy People 2020 targeted percentages for screening for hearing loss no later than age 1 month is 90.2%, receipt of audiologic evaluation no later than age 3 months for infants who did not pass the hearing screening is 72.6%, and enrollment of infants aged 6 months and under for intervention services no later than age 6 months is 55.0%.

The EHDI Act of 2010. The EHDI Act of 2010 amended Section 399M of the Public Health Service Act (42 U.S.C. 280g-1) by revising the program purposes to include:

- Developing and monitoring the efficacy of statewide programs and systems for hearing screening of newborns and infants; prompt evaluation and diagnosis of children referred from screening programs; and appropriate education, audiological, and medical interventions for children identified with hearing loss.
- Developing efficient models to ensure that newborns and infants who are identified with a hearing loss through screening receive follow-up by a qualified healthcare provider.
- Ensuring an adequate supply of qualified personnel to meet the screening, evaluation, and early intervention needs of children (National Center for Hearing Assessment and Management [NCHAM], 2011a).

Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB). The goal of the universal newborn hearing screening and intervention (UNHSI) program in the HRSA/MCHB is to reduce "the loss to follow-up (LTF) of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery by utilizing specifically targeted and measurable interventions" and "…to further focus efforts to improve the loss to follow-up/loss to documentation (LTF/LTD) by utilizing specific interventions to achieve measurable improvement in the numbers of infants who receive appropriate and timely follow-up" (HRSA, 2013).

The UNHSI program in HRSA/MCHB awards competitive grants to support state EHDI systems in their efforts to ensure that all newborns receive an NHS and all recommended follow-up services. Currently HRSA/MCHB has awarded 58 grants to states, territories, and the District of Columbia. The UNHSI program also has a cooperative agreement with Utah State University to provide technical assistance and consultation through NCHAM (HRSA, 2011).

Beginning in 2006, the UNHSI program has sponsored a series of learning collaboratives organized by the National Initiative for Children's Healthcare Quality (NICHQ) to develop activities that reduce the number of infants and families who are lost to follow-up. Ten promising changes were identified (see *Table 1*), but the single most effective means of reducing the LTF rate is the assignment of a dedicated follow-up coordinator (HRSA, 2013).

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Table 1
Promising Practices to Reduce LTF NICHQ Learning Collaborative

1	Standardize or "script" the message given to the parents when an infant does not pass the initial screening test.
2	Standardize the process for collecting additional contact information for infants who do not pass their screening. Get a second point of contact for the family (e.g., telephone number of a relative or friend).
3	Verify the identity of the PCP or clinic responsible for follow-up with both the parent and assigned provider at the time the infant is screened before the family leaves the hospital.
4	Schedule a follow-up appointment (rescreening or diagnostic evaluation appointment) at the time that the infant does not pass the screening—before the family leaves the hospital—and stress its importance
5	Call the family before the diagnostic audiology appointment to verify the appointment time and place and include the reasons why the appointment is important. Offer assistance to get to the appointment, if necessary (e.g., transport vouchers).
6	Make two audiology appointments when scheduling diagnostic evaluations, so that the infant who cannot be completely evaluated at the first appointment is scheduled to return within a reasonable timeframe. Cancel the second appointment, if not needed.
7	Use a fax-back form at the time of diagnostic evaluation to alert the PCP of the results and need for follow-up.
8	Use fax-back forms between all parts of the care continuum (audiology, PCP, specialists, early intervention).
9	Obtain consent from parents for release of information at first contact with early intervention, so that information can be shared between early intervention, the PCP, and the state EHDI database.
10	Provide PCPs with early intervention reports with clinically useful and timely information for providers.

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Centers for Disease Control and Prevention

The EHDI program of the CDC currently funds 52 cooperative agreements to states, territories, and the District of Columbia to support the development and implementation of EHDI tracking and surveillance systems (CDC, 2011c). The purposes of the CDC EHDI program are:

- To assist EHDI programs in developing and maintaining a sustainable, centralized NHS tracking and surveillance system capable of accurately identifying, matching, collecting, and reporting data on all occurrent births that is unduplicated and individually identifiable through the three components of the EHDI process (screening, diagnosis, and early intervention).
- For those programs with fully developed EHDI information systems (EHDI-IS), enhance electronic system capacity to collect data; ensure children receive recommended screening and follow-up services; and exchange data accurately, effectively, securely, and consistently between the EHDI-IS and Electronic Health Record Systems (EHR-S)

with a specific focus on reducing the duplicate data entry burden and a reduction in recommended LTF services (screening, diagnosis, and intervention; CDC, 2011a).

The CDC collects data from state EHDI programs annually through the voluntary EHDI Hearing Screening and Follow-up Survey (EHDI-HSFS). The survey collects aggregate data, based on individually-identifiable records, about NHS and follow-up, audiologic evaluations, and early intervention services.

The CDC and state representatives developed seven national goals that illustrate the comprehensiveness of EHDI programs and reflect the ideal achievement (see *Table 2*). Two of the CDC EHDI goals focus on the role of data systems in reducing LTF: Goal 6 states that every state will have a complete EHDI tracking and surveillance system that will minimize LTF, and Goal 7 plans for every state to have a comprehensive system that monitors and evaluates the progress towards the EHDI goals and objectives (CDC, 2011b). The CDC's (2003) EHDI Program Guidance Manual provides a listing of the components needed for a comprehensive tracking, reporting, and follow-up system (see *Table 3*).

An effective link between health and education professionals is needed to ensure successful transition and determine outcomes of children with hearing loss for planning and establishing public health policy.

National Guidelines

The Joint Committee on Infant Hearing (JCIH) 2007 position statement is the most widely recognized practice guideline relative to all components of EHDI. The statement specifies that states should implement data management and tracking systems as part of an integrated child health information system to monitor the quality of EHDI services and provide recommendations for improving systems of care. They specify that an effective link between health and education professionals is needed to ensure successful transition and determine outcomes of children with hearing loss for planning and establishing public health policy. The document outlines eight overarching principles that provide the foundation for EHDI systems. Principle 8 makes the recommendation that information systems should be designed and implemented to interface with electronic health charts and should be used to measure outcomes and report the effectiveness of EHDI services at the patient, practice, community, state, and federal levels (JCIH, 2007).

Table 2
EHDI National Goals

Goal 1

All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.

Goal 2

All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.

Goal 3

All infants identified with a hearing loss will receive appropriate early intervention services before 6 months of age.

Goal 4

All infants and children with late onset, progressive, or acquired hearing loss will be identified at the earliest possible time.

Goal 5

All infants with hearing loss will have a medical home.

Goal 6

Every state will have a complete EHDI tracking and surveillance system that minimizes LTF.

Goal 7

Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI goals and objectives.

Table 3
The Centers for Disease Control and Prevention Program Objectives (CDC, 2003)

Comprehensive System	Policies & Procedures	Privacy & Confidentiality
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.	Each state will have written policies and procedures regarding their EHDI tracking and surveillance system.	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	Risk Factors for Hearing Loss	NHS Results
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.	The state EHDI tracking and surveillance system will ascertain risk factors for hearing loss for every infant by linkage with other state data systems.	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 Healthcare Providers	Identifying Children Who Need Screening & Follow-Up	Access to Information
Each state will provide a mechanism for hospitals, audiologists, and other healthcare providers to report NHS results, evaluations, and interventions.	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.	The state EHDI tracking and surveillance system will allow case managers and authorized healthcare providers to access relevant information about infants and children.

State EHDI Programs

Although all states and jurisdictions have EHDI programs, not all have legislation that addresses NHS and/or EHDI. Beginning with Hawaii in 1990 and Rhode Island in 1992, there are now at least 44 jurisdictions with legislation, although the scope of these statutes varies (NCHAM, 2011b). Some set the benchmark as low as 85%, while others don't require small hospitals to provide hearing screening. Birthing facilities are required to report NHS data to the State Department of Health in 29 states, although the type of data can vary from aggregate data to individual screening results. Most states consider NHS to be the standard of care for newborns, with only 14% requiring written parent informed consent. Less than one-third of the states indicate that NHS is covered by health insurance policies.

While legislation defines the minimum required activities, many states and jurisdictions conduct considerably more comprehensive programs.

State EHDI programs are structured differently, depending not only upon statutes and regulations but also upon factors such as:

- Placement within state and jurisdiction administrative systems.
- Resource availability.
- Geographic limitations.
- Populations served.

While legislation defines the minimum required activities, many states and jurisdictions conduct considerably more comprehensive programs that typically result in tracking services and/or data in five components:

- NHS
- Audiologic diagnostic testing
- Early intervention
- Medical home
- Family-to-family support

States also differ in their approaches to collecting and processing data that influence their tracking, reporting, and follow-up efforts. The JCIH 2007 position statement acknowledged that the CDC's provision of funds to EHDI programs has been instrumental in linking hearing screening data with other child health data sets, including electronic birth certificates, vital statistics, birth defects registries, metabolic or "dried blood-spot" screening, and immunization registries (JCIH, 2007).

In a 2005-2006 evaluation of the UNHSI program, Mathematica Policy Research, Inc., reported different approaches for hospital reporting of NHS data to EHDI programs. The methods that hospitals used to report results, either solo or in combination with other methods, are shown in *Table 4*.

It was reported that systems based on handwritten data were more prone to errors. Other common errors were missing contact information, missing hearing results, and name changes for the baby.

Table 4
Methods Hospitals Used to Report Results

Reporting Method	Used Exclusively or in Combination with Other Methods
Mailed or faxed paper forms	62%
Software specifically designed to report the results	30%
Metabolic screening cards	25%
Electronic birth certificates	17%
Email, other electronic methods, or data mailed on disks	40%

Errors and missing information can be a critical factor in preventing timely and accurate follow-up. An advantage of reporting results with the electronic birth certificate is that missing results are easily identified, and information about the family or medical home can more easily be accessed (Mathematica Policy Research, n.d.). Suggested strategies to improve the use of data included:

- Using web-based systems to transmit results and contact information.
- Using web-based systems to track follow-up.
- Establishing data-sharing procedures.
- Securing family permission for data sharing (Shulman & Beculides, 2007).

Inpatient Birthing Facilities and Screening Sites

Without efficient tracking, reporting, and follow-up at the hospital level, screening is meaningless.

The hospital's role is integral to ensuring that timely follow-up occurs. Screening staff are in an ideal position to gather and document pertinent information that will help improve the chances that efficient follow-up can occur. A hospital-based NHS program encompasses a coordinated flow of activities that involves much more than just conducting a screening. Without efficient tracking, reporting, and follow-up at the hospital level, screening is meaningless. Hospitals implement policies and procedures to make sure that all bases are covered, and there is accountability, accuracy, and efficiency in all program activities. It is important to gain an understanding and appreciation for the inpatient hospital process and the comprehensive nature of their critical role and responsibilities. *Table 5* outlines an overview of typical inpatient hospital activities involving tracking, reporting, and follow-up.

It is important to be aware that hospitals are challenged by multiple factors that can compromise the quality and integrity of the data, tracking, and follow-up procedures. Hospitals are often faced with significant internal challenges, such as staffing shortages, high rates of turnover, and excessively long shifts. Nurses and other hospital staff conducting screenings often have multiple responsibilities and patients to attend to. Checks and balances must be in place with a system of accountability for all program activities.

Out-of-Hospital Births

In 2012, the CDC reported that 1.4% of babies born were out-of-hospital births. Although only a small percentage of all U.S. births, there is heightened national awareness and state EHDI efforts to increase the number screened by 1 month of age. The first CDC EHDI goal focuses on screening all infants for hearing loss prior to discharge with a program objective that all states have a mechanism for screening out-of-hospital births (CDC, 2011c).

A survey conducted by the AAP highlighted six states' statistics and steps taken to reduce LTF and increase the number of out-of-hospital birth screenings (EHDI Email Express, 2011). Some of the highlights from the responding states include:

- Education regarding the importance of EHDI.
- Collaboration with midwifery agencies and organizations.
- Providing screening equipment.
- Technical assistance and training.
- Sending parents letters and information regarding the benefits.
- Providing quarterly reports with screening statistics to practitioners.

Outpatient Providers and Services

The success of outpatient tracking, reporting, and follow-up is dependent upon the accuracy, timeliness, and comprehensiveness of NHS data. The data goes beyond the results of the hearing screening event and includes maternal and healthcare provider information, recommended follow-up activities, and other factors to facilitate the completion of the follow-up activities.

Table 5
Overview of Typical Inpatient Hospital Activities Involving Tracking, Reporting, and Follow-Up

Overview 1. Identifying all new births and entering demographic data into the screening equipment and/or directly into the state's EHDI tracking and surveillance system through a secure web portal.

Individual states reporting requirements dictate which data elements are reported, the periodicity of reporting, and the mechanism used to report. Recent advances in data integration efforts and activities have allowed hospitals to improve the accuracy and integrity of their data and minimize the need for manual demographic data entry. Along with screening results, data elements commonly reported by hospitals to the state EHDI program are:

- The medical identification number assigned by the hospital
- Last and first name (if known)
- Date of birth
- Gender
- Single versus multiple births
- Nursery level (well-baby nursery versus NICU)
- Hospital name
- Name of screening site
- Name of primary care physician
- Screener's name

Other elements, such as type of insurance, maternal information, and existing risk indicators for late onset and progressive hearing loss, may be required. Accuracy in entering each of these elements is critical for optimal matching capabilities and the enhancement of hospital and state EHDI follow-up efforts.

Overview 2. Rescreening, if needed.

If the baby does not pass the initial screening, a repeat screen may be needed prior to discharge. Hospital tracking procedures must be in place to flag these babies and ensure the screening process is complete prior to discharge. Proper training is important to minimize manual data entry errors in the screening equipment and/or tracking and data management system, which could lead to the creation of duplicate screening records. Most equipment has the ability to recall previously entered records, which helps to minimize the need for manually re-entering already existing demographic information.

Overview 3. Documentation of screening results.

After the screening is completed, results are documented according to hospital procedures. This may require manual documentation and/or entering results electronically into a facility's electronic health or medical record system.

Overview 4. Communicating results to parents and educating them on next steps.

Results must be relayed to parents, and if a passing result was not obtained prior to discharge, parents need to be informed, and a plan for follow-up must be discussed. Contact information must also be obtained to connect with the family prior to the appointment and remind them if they are to return for an outpatient rescreen or evaluation.

Overview 5. Communicating results to the attending physician and the medical home.

If the baby does not pass the screening, the baby's healthcare providers (i.e., attending physician and primary care provider) should be informed. Their role is critical in reinforcing the importance of follow-up and providing assistance to the family, if needed. Hospitals have different mechanisms in place to relay this information in a timely manner.

Table 5 (continued)

Overview 6. Data transmission.

For the purpose of tracking, reporting, and follow-up, screening data must be regularly and accurately reported to the state EHDI tracking system. States vary in the mechanism used to report. For example, in some states, data is transferred seamlessly from the screening equipment to a data management program within the hospital and/or directly into the state EHDI tracking system. In this case, the type of equipment a hospital is using and its compatibility with the data management system may determine whether the data is manually entered or whether an automated process of exporting and merging may be used. Other states use the bloodspot specimen card to report results. Regardless of the process used, accuracy in entering each of these elements is critical for optimal matching capabilities and to enhance the chances of effective tracking and monitoring.

There are a variety of reasons why screening outcomes may be something other than a pass or refer/fail. These outcomes include:

- Babies that are missed.
- Babies that are deceased.
- Babies that are transferred to a different hospital or facility prior to screening.
- Parental refusals.
- Incomplete screening due to equipment malfunction.
- Early discharge.
- Screening deferred to audiological evaluation for medical reasons or due to craniofacial anomalies.
- Other risk factors.

Because most screening equipment require some level of manual data entry, human error can occur and compromise the quality and integrity of the data. Improved technology is needed to automate the process of populating data fields in screening equipment software.

Overview 7. Program evaluation.

In order for hospital screening programs to monitor the effectiveness of their tracking and follow-up efforts, ongoing program evaluation is needed. The effectiveness of each program component (i.e., inpatient and outpatient screening refer rates, individual screener refer rates, the number of babies screened as compared to the number of babies born according to vital records, timeliness of data submission) is critical and will have an impact on follow-up outcomes. The JCIH 2007 position statement has outlined various benchmarks and quality assurance measures to help guide these efforts. Some commercial EHDI data management systems provide report templates to evaluate these data, and several state programs have developed various surveys and tools that are also available on the NCHAM website at http://www.infanthearing.org/datamanagement/index.html and http://www.infanthearing.org/programevaluation/evaluationtools.html#hospitalinfanthearing.org

Photo courtesy of John Tracy Clinic

Depending upon state or jurisdiction statutes, regulations, and protocols, the first outpatient procedure may be either an additional hearing screening or a comprehensive audiologic evaluation. The type of follow-up procedure may also be determined by previous hearing screening results or by risk factors, as identified in Appendix 1 of the JCIH 2007 position statement.

Depending upon the results of the initial outpatient procedure, the next steps for the baby may become more complex and less easily understood by the family. For babies identified with a permanent hearing loss, referrals to medical specialists, including an otologist, ophthalmologist, and geneticist (to determine the etiology of the hearing loss), may require extra encouragement and special considerations for some parents to complete. Consistent with American Speech-Language-Hearing Association's counseling guidelines, it is important for the audiologist to provide informational and adjustment counseling as the baby is referred to these specialists, and the family is guided through the process of accessing and understanding the services (American Speech-Language-Hearing Association, 2008a). Further information regarding parent and family counseling may be found in the appropriate chapters of this publication.

Photo courtesy of Centers for Disease Control and Prevention

As the number of professionals involved with the baby's diagnosis and treatment increases, the need to exchange accurate, timely, and complete information among the providers becomes more critical, and coordination becomes more complex. The baby's primary care provider (PCP), serving as the medical home, has a primary role in referring the baby for specialty medical services (Wiley, n.d.), coordinating those services, and empowering the parents. The pediatric audiologist serves a similar role with regard to the baby's hearing loss; its impact on development, technology and communication modality options; and referral and coordination of services. If eligible for Part C services, the service coordinator fulfills a complementary role of ensuring that resources are accessed to meet the infant's developmental needs and also to meet the needs of the family to support the child's growth and development.

To begin the typical outpatient follow-up process, accurate identification of the PCP (the baby's medical home) is crucial, as is contact information for the baby's parent(s)/guardian(s). EHDI programs have different follow-up protocols, but an informal survey of the members of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (Hoffman & Farrell, 2008) found that most utilize letters, phone calls, and/or faxes to the baby's PCP and/or parent(s)/guardian(s). Written notifications are often generated from the EHDI program's electronic data systems. This notification of inpatient hearing screening results and recommended follow-up by the EHDI program should not be the first notice, however. Effective education of the parent by the hospital staff and/or physician, explanation of the hearing screening results, and determination of the next follow-up step sets the groundwork for a more seamless and effective handoff between the inpatient and outpatient systems. Ideally, an appointment for the outpatient rescreening or evaluation

should be made prior to the baby's discharge. The inpatient results should be provided to the receiving professional, as well as the parent and the baby's PCP. Results should be explained to parents in a manner that is clearly understood—keeping in mind linguistic, cultural, and literacy factors. The results should be sent (preferably faxed) to the referring physician, the state EHDI program, and any other professionals to whom the baby has been referred.

Audiologic evaluation data received by the state EHDI program has multiple purposes. First and foremost, it is necessary to confirm that the baby is receiving the recommended or mandated follow-up services specified in the state statutes, regulations, or protocols. The data also serves to help coordinate follow-up services among various service providers, especially as EHDI programs evolve to become more of a central hub for multiple services. Data is also used for quality assurance purposes and for statistical analyses at the local, state, and national levels. Specific data elements and preferred reporting formats will vary by state and jurisdiction. Coordination between the state EHDI program and audiologists will help to ensure that the reporting of evaluations will support and enhance the state's tracking and follow-up efforts.

For babies identified with a permanent congenital, progressive, or later-onset hearing loss, referral to early intervention services and documentation of the results is an important, though challenging, aspect of documenting the efficacy of EHDI programs. Part C—known by various names in different states or jurisdictions—is often the coordinated point of entry to early intervention services for the parent(s) when a baby has been identified with hearing loss. Because of the Family Education Rights and Privacy Act (FERPA) and the Part C Privacy Regulations, parent consent is needed for the sharing of enrollment and developmental progress reports (Houston, Behl, White, & Forsman, 2010). Increasingly, EHDI programs are developing strategies to provide more effective follow-up through written agreements with Part C. Some families, however, may opt for private services or other public agencies that provide early intervention services for very young children who are deaf or hard of hearing. These may include private schools, Early Head Start programs, and speech-language pathology clinics.

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Family support services are becoming an integral component of the EHDI system and also provide challenges in tracking, reporting, and follow-up. States are developing systems to include family-to-family support programs, such as Guide By Your Side, into the EHDI program that facilitate referrals and reporting. Others are supporting and developing more informal networks of families that, while they may be valuable to the families, provide data on an aggregate level at best and do not allow for tracking and follow-up with individual babies who are deaf or hard of hearing.

Special Considerations for Follow-Up

"Border Babies." Border babies present a unique challenge to EHDI programs because of the need to cross state or jurisdictional boundaries for tracking, reporting, and follow-up. The classic case of a border baby is one who is born in one state but is a resident of a different state. The question emerges as to which EHDI program has responsibility for following that baby: the state of birth or the state of residence or both or neither? The answer may depend upon state statutes, regulations, and protocols. In situations where both programs are trying to follow-up, PCPs and parents may be getting duplicate requests with different recommendations. If neither state is following-up, the baby's family is not receiving support or guidance from either EHDI program. Even in situations where it is clear which state has the responsibility to follow-up, it may still not be clear which state's protocols and services are to be accessed.

A common variation of the border baby issue occurs when a baby is born in its state of residence but is transferred to another hospital, particularly an NICU, in a different state. The receiving hospital may not have a mechanism available to report the NHS results to the EHDI program in either the birth state or the state of the receiving hospital. Once again, developing reporting processes between the EHDI programs, or even directly with the receiving hospitals, can facilitate the timely reporting of inpatient hearing screening results and the provision of appropriate follow-up services, if needed.

Increasingly, "border baby" issues are being negotiated between the EHDI programs in adjoining states and jurisdictions through memoranda of agreement, so that it is clear which program is providing tracking and what type of follow-up services are being recommended. Five New England states have signed a NHS Interstate Exchange Agreement (Farrell, personal communication, 2011) to share hearing screening data when an infant resides in a member state different from the birth state.

"Loss to Follow-up/Loss to Documentation." LTF is a challenging issue facing the EHDI system nationally. LTF occurs when a baby does not receive the recommended follow-up services. It may occur at any point in the EHDI process. A baby who does not pass the birth admission screening may not receive the recommended outpatient rescreening or audiologic evaluation. A baby who does not pass the final hearing screening may not receive all of the recommended audiologic evaluations to the point of determining if hearing is normal or a permanent hearing loss exists. A baby who has been identified with a permanent hearing loss may not receive early intervention services. LTF occurs for many reasons. For example, parents are not informed of the next steps or do not understand what is expected, the baby's primary healthcare provider may not refer for the follow-up evaluation, or the appropriate services may not be readily available and accessible.

Photo courtesy of NCHAM

Another group of babies about which EHDI programs are missing data are those classified as "lost to documentation (LTD)" (Mason, Gaffney, Green, & Grosse, 2008). Babies in this group are those who have received services, but results have not been reported to the EHDI program, and, therefore, cannot be documented. In a study of LTD in dried bloodspot screening programs, Hoff, Hoyt, Therrell, and Ayoob (2006) found that name changes, data mismatches, incomplete or erroneous parent contact information, and unknown PCP contributed to LTD.

In its annual EHDI-HSFS, the CDC collects aggregate data about infants with "no documented diagnosis/ undetermined." This includes infants whose parents declined services, are nonresidents, moved out of the jurisdiction, who are in process, or who died. Infants who comprise the LTF/LTD group are those with "no documented diagnosis" for three of these reasons: (1) parents were contacted but were unresponsive, (2) parents were unable to be contacted, or (3) unknown reasons (CDC, 2013).

Although all states and jurisdictions have implemented NHS programs, appropriate and timely follow-up for infants who need further testing continues to be a major problem. Overall, there has been a steady reduction in the percentage of infants who are categorized as LTF and/or LTD from newborn hearing screening. The annual EHDI-HSFS indicates that the average LTF rate has improved from 47.7% in 2006 to 35.9% in 2011. However, the LTF rates vary considerably from state to state—ranging from 3.0% to 83.6% (CDC, 2014).

It is often only by chance that an outpatient screening or audiologic report may mention the state of birth and provide the necessary information to assist the EHDI program in the state of birth to identify an outcome for that particular baby.

There are many factors that can contribute to LTF/LTD. The Massachusetts Department of Public Health identified several maternal and child factors that were associated with an increased likelihood of being lost to follow-up in the EHDI system (Liu, Farrell, MacNeil, Stone, & Barfield, 2008). Factors that increased the risk of being lost to follow-up between NHS and audiologic evaluation were:

- Maternal race/ethnicity.
- Maternal smoking during pregnancy.
- Public insurance coverage.
- Area of residence within the state.

Factors associated with LTF between diagnosis and early intervention included the degree of hearing loss (mild, moderate, and unilateral hearing loss), normal birth weight, and area of residence within the state.

A somewhat different set of circumstances contributes to the classification of LTD (or perhaps LTF) when a baby who is born in its state of residence moves to another state before follow-up services are completed. This may happen with military families who are reassigned, families who relocate to a different state, or babies who are adopted by families residing in a state different from that of the baby's birth. It is often only by chance that an outpatient screening or audiologic report may mention the state of birth and provide the necessary information to assist the EHDI program in the state of birth to identify an outcome for that particular baby.

Family and child factors are not the only ones to consider when evaluating LTF/LTD rates. American Speech-Language-Hearing Association's Technical Report on LTF (American Speech-Language-Hearing Association, 2008b) identified system issues that contribute to LTF/LTD. These issues include:

- PCPs
- Family education
- Service provider communication
- Privacy regulations
- Personnel involved (see *Table 6)*

A reduction in the rate of LTF/LTD will require the EHDI program to focus on each of these system areas and to develop strategies, such as those that have been found to be effective in the NICHQ learning collaborative (see *Table 1*).

In 2009, HRSA/MCHB provided supplemental grant funding to EHDI programs to increase their level of effort to reduce LTF based on the effective practices identified during the NICHQ learning collaboratives. An analysis of 29 narratives in the supplemental grant applications posted to the NCHAM website (NCHAM, 2010) found that, in addition to the strategies identified in the learning collaborative, EHDI programs were focusing on strategies that are based on their particular EHDI system. In addition to implementing the NICHQ effective practices, the primary types of strategies in the grant applications to reduce LTF were:

- Family support activities.
- Data system upgrades
- Integration with other child health data systems.
- Parent education materials.
- Quality measures.
- Equipment funding through a variety of mechanisms.
- Education for audiologists and hospital screening staff.
- EHDI staff being more involved in follow-up with families and professionals.
- Improved reporting to PCPs by hospital staff, audiologists, and EHDI staff.
- Increased awareness by professionals and the public (Hoffman, 2010).

Table 6
Factors Contributing to LTF (American Speech-Language-Hearing Association, 2008b)

Primary Care Providers (PCP)	Family Education	Service Provider Communication
Since the PCP is often the focus of EHDI follow-up efforts, accurate identification of the baby's PCP by the birthing facility is important. The PCPs should have strategies in place if notification does not happen and should be familiar with referral sources in their community.	Parents have expressed a desire to be informed about hearing screening prior to the screening, the urgency of follow-up, and to be present during the event. For this to occur, hospital personnel will need additional training to meet these needs.	The lack of communication among providers is a barrier to successful follow-up, as is the lack of integrated data systems for data sharing.

Personnel Involved	Privacy Regulations
Audiologist involvement in newborn hearing screening programs may result in better follow-up outcomes. Thomson (2007) found that infants were 27% more likely to receive the recommended outpatient follow-up if audiologists were involved with the hospital's newborn hearing screening program.	The sharing of information among providers can be adversely influenced by privacy regulations, primarily the Health Insurance Portability and Accountability Act (HIPAA, 1996), Family Education Rights and Privacy Act (FERPA, 2004), and Part C Privacy Regulations (IDEA, 2004). ***HIPAA.*** Public Law 104-91, § 164.212 identifies the uses and disclosures for which an authorization or opportunity to agree or object is not required: "A covered entity may disclose protected health information for the public health activities and purposes . . . to a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events, such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions." ***FERPA*** 20 U.S.C. § 1232g; 34 CFR Part 99 protects privacy of student education records and requires written parent consent to release health information to EDHI programs. ***Part C Privacy Regulations*** confidentiality regulations begin when child has been referred to Part C, and prior written informed consent is needed to share information outside of the Part C system. Written authorization for referrals to Part C may not be required (Houston, Behl, & White, 2008; Surprenant, 2006), because disclosure is mandated by law (i.e., IDEA, 2004) and the information is to be shared for public health purposes.

The primary purpose of tracking, reporting, and follow-up is to ensure that all babies are screened . . . and provides the basis for measuring a state EHDI program's effectiveness, validity, progress, outcomes, strengths, and weaknesses.

In 2009, 49 EHDI coordinators participated in a strengths-weaknesses-opportunities-threats (SWOT) survey of their programs—identifying key factors in 12 program areas, including LTF (Hoffman, Muñoz, Bradham, & Nelson, 2011). The analysis of the coordinators' 277 responses in the LTF area identified the top themes from the SWOT survey, and a threats-opportunities-weaknesses-strengths (TOWS) analysis of the SWOT data yielded four recommendations (see *Table 7*).

Summary

The primary purpose of tracking, reporting, and follow-up is to ensure that all babies are screened, and those in need of further testing, evaluation, or intervention receive comprehensive, appropriate, and timely services. Equally important, however, is that data generated through a comprehensive tracking, reporting, and follow-up system provides the basis for measuring a state EHDI program's effectiveness, validity, progress, outcomes, strengths, and weaknesses. Being able to demonstrate progress relative to goals, objectives, and outcomes can be powerful in showing that specific milestones and benchmarks have been met.

EHDI programs are working diligently to reduce the number of babies who are lost to follow-up/lost to documentation. Key elements to reduce this number are professionals who are knowledgeable about the EHDI system and collaborative in their approach, effective strategies to engage families who experience challenges in following through, and integrated data systems capable of supporting the hearing screening and follow-up activities of the more than 4.3 million babies born each year in the United States..

Table 7
Strengths-Weaknesses-Opportunities-Threats (SWOT) Survey

Threats-Opportunities-Weaknesses-Strengths (TOWS) Analysis of SWOT Data Recommendations

1 Existing positive relationships with parents and professionals can be used to engage additional stakeholders in reaching out to other groups and individuals, adopting effective practices, linking families to the recommended services, and enlisting advocates.

2 Continual development of comprehensive data systems that are linked to other child data systems are easy to use and accessible by providers, efficiently support follow-up efforts, and provide for program and system evaluation.

3 Reporting, tracking, and follow-up protocols must be refined to incorporate effective practices, focus on families most at risk of being categorized as LTF, and maximize the efficiency of conducting follow-up to ensure that the recommended services are received and reported.

4 Health disparities must be reduced, especially for high-risk groups and those in unserved or underserved areas.

SWOT Survey Top Themes

Strengths

Relationship building, coordinated tracking protocol, and program improvement.

Weaknesses

Protocol, limited personnel, and access to care.

Opportunities

Relationship building, data tracking systems, and access to state systems.

Threats

Funding, interagency cooperation, and family circumstances.

References

American Academy of Pediatrics. (2011). Reducing loss to follow-up in out-of-hospital birth populations. *EHDI Email Express.* Retrieved January 15, 2011, from http://www.medicalhomeinfo.org/downloads/pdfs/Feb2011_EHDI_Email_Express.pdf

American Speech-Language-Hearing Association. (2008a). *Guidelines for audiologists providing informational and adjustment counseling to families of infants and young children with hearing loss birth to 5 years of age* [Guidelines]. Retrieved August 6, 2009, from www.asha.org/policy

American Speech-Language-Hearing Association. (2008b). *Loss to follow-up in Early Hearing Detection and Intervention* [Technical Report]. Retrieved August 6, 2009, from www.asha.org/policy

Centers for Disease Control and Prevention (CDC). (2003). *Early Hearing Detection and Intervention program guidance manual.* Atlanta, GA: Author.

Centers for Disease Control and Prevention. (2011a). *Development, maintenance, and enhancement of Early Hearing Detection and Intervention information system (EHDI-IS) surveillance programs.* Funding opportunity number: CDC-RFA-DD11-1101.

Centers for Disease Control and Prevention. (2011b). *Early Hearing Detection and Intervention (EHDI) national goals.* Retrieved December 14, 2011, from http://www.cdc.gov/ncbddd/hearingloss/ehdi-goals.html

Centers for Disease Control and Prevention. (2011c). *Information about Early Hearing Detection and Intervention (EHDI) state programs.* Retrieved December 14, 2011, from http://www.cdc.gov/ncbddd/hearingloss/ehdi-programs.html

Centers for Disease Control and Prevention. (2013). *2011 annual data Early Hearing Detection and Intervention (EHDI) program.* Retrieved February 20, 2014, from http://www.cdc.gov/ncbddd/hearingloss/ehdi-data2011.html

Centers for Disease Control and Prevention. (2014). *2012 summary of diagnosis and loss to follow-up/loss to documentation in 2012.* Retrieved January 8, 2015, from http://www.cdc.gov/ncbddd/hearingloss/2012-data/2012_lfu_summary_web_b.pdf.

Family Educational Rights and Privacy Act, 34 C.F.R. Part 99. (2004).

Health Insurance Portability and Accountability Act of 1996, P.L. 104-191.

Health Services and Resources Administration. (2013). *Reducing loss to follow-up after failure to pass newborn hearing screening.* Funding Opportunity Announcement, HRSA 14-006. Retrieved on October 29, 2013, from https://grants.hrsa.gov/webExternal/SFO.asp?ID=5772b363-21fe-40f0-8216-27673cc6e5a2.

Health Services and Resources Administration. (2011). *National Center for Hearing Assessment and Management.* Retrieved December 19, 2011, from http://www.hrsa.gov/communitiesofpractice/AtaGlance/hearingassessment.pdf

Hoff, T., Hoyt, A., Therrell, B., & Ayoob, M. (2006). Exploring barriers to long-term follow-up in newborn screening programs. *Genetics in Medicine, 8*, 563-570.

Hoffman, J. (2010). Managing loss to follow-up in Early Hearing Detection and Intervention systems. *ASHA Audiology 2010 Online Conference: Early Hearing Detection and Intervention (EHDI).* Retrieved October 13, 2010, from http://www.asha.org/eweb/OLSDynamicPage.aspx?webcode=olsmainpage

Hoffman, J., & Farrell, J. (2008). *Status report—ASHA task force on loss to follow-up. Unpublished survey.* Directors of Speech and Hearing Programs in State Health and Welfare Agencies, Inc.

Hoffman, J., Muñoz, K., Bradham, T., & Nelson, L. (2011). Loss to follow-up: Issues and recommendations. *The Volta Review*, *111*(2), 165-180.

Houston, K. T., Behl, D., & White, K. (2008). *EHDI challenges and strategies in addressing privacy regulations*. Retrieved July 21, 2008, from http://www.infanthearing.org/meeting/ehdi2008/topical

Houston, K. T., Behl, D., White, K., & Forsman, I. (2010). Federal Privacy Regulations and the Provision of Early Hearing Detection and Intervention programs. *Pediatrics*, *126*, S28-S33.

Individuals with Disabilities Education Improvement Act of 2004, P.L. 108-446.

Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *Pediatrics*, *120*, 893-921.

Liu, C., Farrell, J., MacNeil, J., Stone, S., & Barfield, W. (2008). Evaluating loss to follow-up in newborn hearing screening in Massachusetts. *Pediatrics, 12,* E1-E9.

Martin, J. A., Hamilton, B. E., Ventura, S. J., Osterman, M. J., Kirmeyer, S., Mathews, T., & Wilson, E. (2013). *Births: Final data for 2012* (USA, Centers for Disease Control and Prevention, National Center for Health Statistics). Retrieved February 22, 2014, from http://www.cdc.gov/nchs/data/nvsr/nvsr62/nvsr62_09.pdf

Mason, C. A., Gaffney, M., Green, D. R., & Grosse, S. D. (2008). Measures of follow-up in Early Hearing Detection and Intervention programs: A need for standardization. *American Journal of Audiology, 17*, 60-67.

Mathematica Policy Research. (n.d.). *Evaluation of universal newborn hearing screening and intervention program–Final report.*

National Center for Hearing Assessment and Management (NCHAM). (2010). *State coordinator toolbox.* Retrieved May 20, 2011, from http://www.infanthearing.org/stategrants/index.html

National Center for Hearing Assessment and Management (NCHAM). (2011a). *EHDI legislation becomes law.* Retrieved on December 14, 2011, from http://www.infanthearing.org/legislation/federal.html

National Center for Hearing Assessment and Management (NCHAM). (2011b). *State EHDI/UNHS mandates: Summaries by provision.* Retrieved on December 14, 2011, from http://www.infanthearing.org/legislative/provisions/index.html

Russ, S., Hanna, D., DesGeorges, J., & Forsman, I. (2010). Improving follow-up to newborn hearing screening: A learning-collaborative experience. *Pediatrics*, *126*, S59-S69.

Shulman, S., & Beculides, M. (2007). *Universal Newborn Hearing Screening and Intervention Evaluation.* Retrieved November 17, 2009, from http://www.infanthearing.org/meeting/ehdi2007/presentations/S4-Shulman.ppt

Surprenant, K. (2006). *How HIPAA and FERPA affect the provision of EHDI services* (Webcast). Retrieved July 24, 2008, from http://learning.mchb.hrsa.gov/ArchivedWebcast.asp?id=144

Thomson, V. (2007). *A programmatic analysis of a newborn hearing screening program for evaluation and improvement*. Unpublished doctoral dissertation, University of Colorado.

U.S. Department of Health and Human Services. (2011). *Healthy People 2020, hearing and other sensory or communication disorders.* Retrieved December 19, 2011, from http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=20

Wiley, S. (n.d.). *Medical care of children with SNHL.* Retrieved November 17, 2009, from http://www.medicalhomeinfo.org/screening/EHDI/EHDI_info_for_providers/Medical_Care_of_SNHL_FINAL.pdf