

Chapter 12

Audiologists Connecting Families to the EHDI Process

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Introduction

Early Hearing Detection and Intervention (EHDI) is the process of identifying infants at birth, or shortly thereafter, who have a hearing loss. It is also the provision of appropriate intervention services to maximize the infant's linguistic and communicative competence. This process may mean different things to professionals who make up the EHDI team. The "team" refers to the infant's family and those professionals who work with the infant to identify the hearing loss and provide the necessary medical, educational, and developmental intervention. Early intervention has a different implication to each member of the team and may have a different meaning depending on that team member's responsibility (see *Table 1*).

To the audiologist, the EHDI team is a family-professional partnership that supports collaborative sharing of all relevant information. It is a partnership,

which is defined as "a relationship of mutual respect between two or more competent persons who have agreed to commit and share their knowledge, skills, and experience in meeting the needs of the child" (SKI-HI Institute, 2004, p. 20).

The responsibilities of the EHDI team are critical. They should be part of a seamless progression of care to provide infants and their families timely and appropriate intervention services. More often than not, these professionals are also involved in the process of guiding families through the often emotionally draining experience of an initial diagnosis of hearing loss for their newborn child. What often gets less attention is the actual transition and support of these families through the maze of referrals and tests after a hearing loss has been identified.

Individual EHDI team members may work diligently to complete their portion of the process; however, communication between other professionals and the infant's caretakers sometimes is neglected.

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Team members may even see the infant concurrently—possibly leading to confusion, misunderstandings, dropped appointments, and families lost to the EHDI process. The audiologist has a unique opportunity and responsibility to facilitate a seamless transition for families and their infants through the EHDI process. The audiologist is often the first professional contacted after a failed hearing screen and the first to diagnose an infant’s hearing loss. Therefore, the test information and recommendations they provide are critical in the decision-making processes of other professionals. So what are the audiologist’s responsibility to infants and their families? How can the audiologist help families connect to the EHDI process?

Newborn Hearing Screenings and Intervention

Approximately 97-98% of all infants born in the United States receive a hearing screen shortly after birth. However, in many areas across the United States, only 35% of infants who fail or miss their newborn hearing screen return for follow-up testing (Centers for Disease Control and Prevention [CDC], 2009). Barriers to follow-up testing may be due to changes in the family’s contact information, financial constraints, language barriers, parents not recognizing the urgency for early intervention, or a lack of a primary medical provider. Families who live in underserved areas may have less accessibility and fewer professional resources available to them (Joint Committee on Infant Hearing [JCIH], 2000). If a child does return for the follow-up screen, referral for a diagnostic audiological evaluation may be delayed due to insurance coverage stipulations, waiting lists at the diagnostic center, or limited transportation. Sometimes, delays may occur due to ill-prepared audiological centers that postpone a diagnosis because they are not infant/toddler focused. In addition, 30-40% of children with hearing loss demonstrate additional disabilities that may affect

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Table 1 The EHDI Team

To the family . . .

EHDI may initially mean nothing. What it comes to mean will depend on the individual services and educational programs received from the audiologist and other members of the EHDI team.

To public health personnel . . .

EHDI may mean the requirement of their state or public health initiative to provide a hearing screen to every newborn infant, intense data management, and follow-up.

To hospital or birthing center personnel . . .

EHDI may mean identifying a program manager and training individuals to provide a hearing screen to every infant born in their facility. It may also mean managing information that is forwarded to the state in compliance with state law.

To audiologists . . .

EHDI may mean audiological screening, a diagnostic battery of tests, counseling, hearing aid fitting, possible Cochlear Implant programming, extensive aural habilitation and communication with numerous healthcare providers.

To physicians . . .

EHDI may mean identification of a medical home, a series of medical tests, x-rays, and medical management with referrals to an otolaryngologist, geneticist, ophthalmologist, cardiologist, or other health professionals.

To the early interventionist . . .

EHDI may mean the process of guiding families through family-centered care to include speech pathology, deaf and hard-of-hearing education services, and/or early childhood special education services.

By adhering as closely as possible to the 1-3-6 guideline, audiologists can obtain an early diagnosis of hearing loss and initiate early intervention as soon as the family is ready to proceed.

communication and related development (American Academy of Pediatrics, 2007) and defer audiological diagnosis to a later time. In order to improve early intervention services and overcome these barriers, greater communication is needed between the members of the EHDI team. The audiologist carries a particular responsibility to facilitate communication with the infant's primary care physician and other EHDI team members.

According to BusinessDirectory.com, professional responsibility is: "Legal and moral duty of a professional to apply his or her knowledge in ways that benefit his or her client, and the wider society, without causing any injury to either" (Luthra, 2012). As custodians of special knowledge regarding the identification and diagnosis of hearing loss, audiologists are constrained by special ethical responsibilities. As such, audiologists must apply this knowledge in ways that benefit the infant and their family.

The importance of early identification of hearing loss has been documented and is well understood by audiologists (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998; Moller, 2000). In audiology, we are fortunate to have position statements that provide a standard of care for infants identified with hearing loss. The JCIH Year 2007 position statement provides timelines or benchmarks for assessment of infants. This timeline is often called the 1-3-6 rule:

1-3-6 Rule

- Newborns screened by 1 month.
 - Infants with hearing loss identified by 3 months.
 - Amplification use begins within 1 month of diagnosis.
 - Infants enrolled in family-centered early intervention by 6 months.
- Ongoing audiological management not to exceed 3-month intervals.

These timelines do not preclude earlier diagnosis and intervention but do provide a reasonable timeframe to initiate audiological diagnosis and follow-up. Audiologists have a professional and ethical responsibility to be vigilant in following these timelines whenever possible—recognizing and being considerate of cultural diversities and the grieving process of families with a newly identified deaf or hard-of-hearing infant. There may be times when adherence to the 1-3-6 guideline is not possible due to medical complications with the infant, finances, mixed feelings, and parental anxiety after the initial diagnosis. However, by adhering as closely as possible to these timelines, audiologists can obtain an early diagnosis of hearing loss and initiate early intervention as soon as the family is ready to proceed. They also enable other EHDI team members who are awaiting audiological information to initiate services for the infant and family in a timely manner.

In order to provide timely and accurate information to the parents and the EHDI team, the audiologist must perform all audiological tests necessary for an accurate diagnosis of hearing loss. Audiologists must use the crosscheck principle—defined as "the desirability of using multiple tests in clinical practice based on the complex nature of the auditory mechanism and the fact that auditory dysfunction may result from pathology at one or more levels" (American Speech-Language-Hearing Association [ASHA], 2004, p. 2). Additionally, the crosscheck principle requires that one test agrees with, or confirms, another test's results, thus providing a reliability check between the two tests for pediatric test protocols (Jerger & Hayes, 1976). Best practices for pediatric assessments are discussed in another chapter of this eBook. They include:

- Comprehensive medical and family history.
- Electrophysiological testing that may include Auditory Brainstem Response (ABR), Tone Burst, Auditory Steady State Response (ASSR), and electrocochleography evaluations (ECOG).

- Immittance testing to include high-frequency tympanometry for infants <6 months of age and acoustic reflex testing.
- Otoacoustic emissions (OAEs).
- Behavioral audiometry testing (when age appropriate).
- Real-ear measurement for appropriate amplification fitting.

In addition, audiologists must perform ongoing monitoring of use of amplification and should provide validation assessments (age appropriate) to ensure successful and meaningful development in language and academic progress. Although there are no mandated national protocols for the assessment of infants, many states have published guidelines for audiologists. These guidelines can be accessed via the National Center for Hearing Assessment and Management website (NCHAM, 2011b).

Pediatric Specialty

Another way of connecting families to the EHDI process is the identification of a key audiologist within a practice or hospital whose primary responsibility is working with infants and toddlers. If there is no such person, then a referral to a site

that specializes in pediatric audiology is critical. A specialty interest in pediatrics may lead to the establishment of a “Center of Excellence” for infants and toddlers. Pediatric Audiology “Center of Excellence” refers to an audiological center that provides follow-up on newborn hearing screening, comprehensive audiological diagnostics, hearing aid fitting, aural habilitation, and ongoing monitoring and care for the deaf or hard-of-hearing infant. It also suggests a center that is “child friendly,” has a child-knowledgeable staff, facilities, services, and equipment to facilitate optimal comprehensive audiological assessment and management (ASHA, 2006, p. 2). ASHA has published documents that further discuss the uniqueness of a pediatric audiology specialty at ASHA Practice Policy Documents (ASHA, 2012). These documents cover scope of practice, knowledge and skills, position statements, practice guidelines, relevant papers, and technical reports.

The American Board of Audiology (2012) has developed a Pediatric Audiology Specialty Certification. The specialty certification examination includes laws and regulations, general knowledge about hearing and hearing loss, child development, screening and assessment procedures, counseling, communication enhancement technology and habilitation/rehabilitation strategies, and educational supports. Families can connect to an ABA audiologist with this pediatric specialty certification at <http://www.boardofaudiology.org/pediatric-audiology-specialty-certification/>.

The CDC has a National Pediatric Audiology Facilities Directory (PALS). EHDI PALS designed to help families of children, birth to 5 years of age, locate appropriate pediatric diagnostic audiology and hearing technology services within their geographical area. This directory can be accessed at <http://ehdipals.org> (EHDI-PALS).

ASHA (2006) indicates that underlying all aspects of an audiology practice serving the pediatric population are four elements:

- Accessible, continuous, comprehensive, coordinated, and compassionate care.



Photo courtesy of Octicon A/S

The pediatric audiologist should demonstrate interpersonal skills that promote effective communication with children, their families, and fellow professionals in the healthcare, early intervention, and educational communities.

- Family-centered and culturally competent care.
- Extensive knowledge of social, emotional, cognitive, and communicative development that serves as the foundation for the optimal development of the whole child and the provisions of developmentally appropriate care.
- Evidence-based practice.

These elements suggest that pediatric audiologists must have the appropriate equipment and protocols for testing newborns and young infants. The audiologist should be able to provide services in a timely manner without an extensive waiting list. He/she should be willing to honor the cultural differences of families when reviewing audiological test results (e.g., providing an interpreter or literature in the family's native language). The audiologist should provide a comprehensive written report in a timely manner that is understandable to the family, as well as to each EHDI team member. This also requires the audiologist be familiar with the procedures of The Program for Infants and Toddlers with Disabilities—or Part C of the Individuals with Disabilities Education Act (IDEA), which includes Individualized Family Service Plan (IFSP) development and procedures for acquiring hearing aids or assistive technology (NECTAC, 2011). “The pediatric audiologist should demonstrate interpersonal skills that promote effective communication with children, their families, and fellow professionals in the healthcare, early intervention, and educational communities” (ASHA, 2006).

Pediatric audiologists may also be responsible for educating and supporting the family's understanding of language options in an unbiased manner. The audiologist should provide the family with information regarding the various communication options and consider providing information in more than one teaching format (e.g., reading materials

in the family's language, Internet sites for in-depth discussion of philosophies, DVD training materials). Today's family is even more computer savvy than generations before, and the audiologist should be aware of the resources available to the family through multimedia outlets.

Selection of amplification and assistive listening devices can be a daunting task for families. The audiologist should be cognizant of the feelings of the family and provide appropriate guidance when it comes to selecting the optimal system for an infant. As with providing information regarding communication options, the audiologist also should consider a multimedia format for family learning. Resources are listed at the end of this chapter to assist families in taking an active role in making decisions for their deaf or hard-of-hearing infant.

Once a hearing loss is suspected, the pediatric audiologist should immediately initiate the referral process to the EHDI team members, specifically early intervention services and the infant's medical home provider. Additional team members should also be informed if they have already been identified (i.e., specialty service providers). Additional audiological testing may be necessary to determine specific thresholds of hearing; however, there should be no delays in referring the infant and family to the other members of the EHDI team. Audiologic practice patterns must bridge universal newborn hearing screening (UNHS) programs with early intervention programs once an infant is identified with a hearing loss.

Connecting families to the EHDI process involves more than providing a hearing screening and diagnostic follow-up and more than providing hearing aids to infants. The pediatric audiologist is charged with educating the team, family, and public concerning the entire EHDI process. Terminology should be demystified and clearly understandable explanations substituted for professional jargon at every opportunity. Expectations and timelines should be clearly identified

to help decision-making by all parties. There are a number of resources available for families and team members (see Appendix A). The pediatric audiologist should consider meeting with parent groups, school programs for the deaf and hard of hearing, early intervention agencies, and medical associations to explain the EHDI process and answer any questions concerning audiological assessment and habilitation.

Materials for providing appropriate information should be varied. An article in the *Journal of the American Academy of Pediatrics* by Moller, White, and Shisler (2006) indicated that primary care pediatricians prefer their knowledge gaps be addressed through:

- Action-oriented resources (algorithms/protocol cards, parent education materials).
- Web-based materials.
- Online continuing medical education (CME) and materials for peer education.

Some excellent materials have been developed for the medical home provider and are available at the National Center for Medical Home Implementation (2012). Additional resources may include the CDC (2011a) website list of Frequently Asked Questions. Resources are plentiful but often are better understood when the pediatric audiologist sits down with the family and reviews the materials.

Another important way pediatric audiologists can connect families to the EHDI process is with systematic information management. An efficient information management system does more than track infants who are tested. Even the simplest of EHDI programs can generate an astounding amount of information, which can quickly overwhelm the capacity of a poorly conceived management system. When all the information necessary to follow-up and track babies is included, program design becomes more complex. Data elements must provide us with EHDI

program performance indicators. They can help the pediatric audiologist monitor how quickly infants are being referred for diagnostic follow-up and if the infant received an evaluation by 3 months of age. An information management system can help flag an infant for a return visit so the infant does not get lost to follow-up. With more than 35% of infants not returning for follow-up after failing the initial hospital screen, this information is critical. An efficient system can generate follow-up letters for return visit schedules for babies diagnosed with hearing loss, as well as for babies who are at-risk for late onset or progressive hearing loss.

Effective information management supports evidence-based practice regarding the documentation of test results, recommendations, and referrals to members of the EHDI team. There are many information management systems available; thus the pediatric audiologist should carefully review each one to find the system that best meets their organization's needs. It could be that the state EHDI program has a particular information management system that they are using. In most cases, state systems include the capacity for the audiologist to directly enter or supply information by fax or mail. It is vital that the audiologist pay close attention to the reporting requirements of the state EHDI system, so infants and their families receive the necessary services in a timely fashion. A list of information management programs can be found on the NCHAM (2014) website. Additional information regarding information management systems may be found in *Chapter 16: EHDI Information Management* of this publication.

Diagnostic Reports

Audiologists can connect families to the EHDI process through written diagnostic reports. It is important to effectively communicate test results to other professionals in unrelated fields. Some considerations when writing reports for the EHDI team are:

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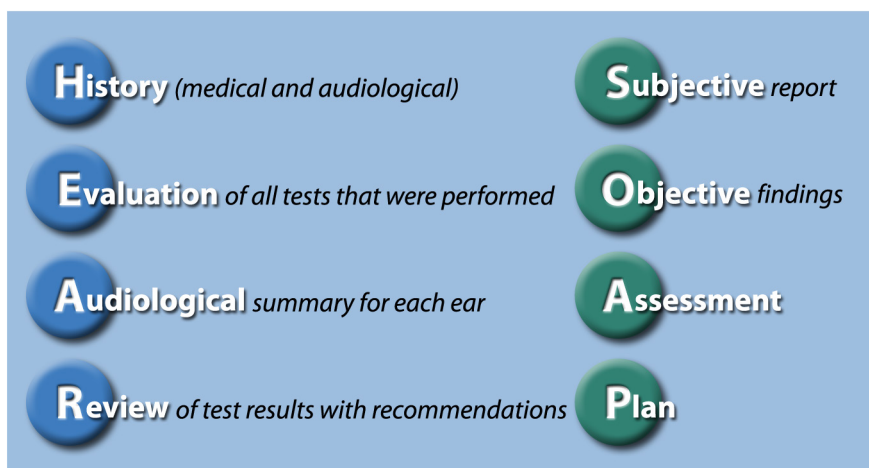
- Does the report address the hearing status of each ear in a clear manner using common terminology? Does the report discuss the functional impact the hearing loss may have for the child?
- Are the recommendations consistent with the test findings?
- Are timely follow-up appointments established when necessary?
- Are referrals made to the appropriate educational and medical facilities?

Audiologists have a professional responsibility to clearly communicate audiological data to others. Even when audiologists have training and skills specific to infants, there is wide variability in the way results are presented in written reports. The report must contain terminology that is professionally accurate, yet clearly communicate findings to both audiologists and other professionals. The summary of the test results should be written with other disciplines in mind. Acronyms should be spelled out to facilitate understanding to those unfamiliar with audiological terminology (e.g., ASSR, ABR, OAE, DNT, SRT). Although physicians and early interventionists may have some knowledge of audiology, it is critical that the audiologist communicate clearly in language the recipient of the report will understand. The audiological profession and its terminology continues to change with the addition of new tests and procedures, making it exceedingly difficult for anyone outside the profession to fully understand new and complex terminology.

To assist families and other professionals in understanding audiological terminology, several websites have been established with comprehensive glossaries and explanation of acronyms. It is

important that the pediatric audiologist either provide that information or direct families and team members to the websites with a listing of commonly used terminology. Examples of this information can be found at My Baby's Hearing (2012). It is also necessary that the audiologist carefully consider the use of complex terminology or audiological jargon when a more simple, functional term may help the recipient better understand what is being reported.

Connecting families to the EHDI process may require audiologists to rethink how to communicate with the team. Because audiologists are known to use acronyms as a way to recall information, perhaps the "HEAR" (aka the old "SOAP") method may be an easy way to remember what every report must contain:



History

History of the case—both medical and audiological—should be reported in any audiological report, as important aspects of an infant's history may contribute to the decision processes of other team members. Some questions the audiologist may ask are:

- Was there a hearing screen at birth? What were the results?
- Have there been subsequent audiological examinations since the newborn hearing screen?

- Were there any medical complications that may put the infant “at-risk” for progressive or late-onset hearing loss?
- Is there a history of otitis media? Were there any surgeries performed for chronic middle ear effusion?
- Is there a family history of hearing loss?

E Evaluation

Evaluation of all objective diagnostic testing should be reported. Was a crosscheck principle used? If certain diagnostic testing was not performed, why was it not performed? It is important that the audiologist not leave team members wondering why certain procedures were or were not performed.

A Audiological

Audiological summaries should state the hearing status of each ear in a clear and concise manner using common terminology. If testing was incomplete for an ear or the hearing status has changed, an explanation should be provided. In addition, the summary should include a description of the functional implications of the hearing loss for the infant in a variety of circumstances—with or without recommended amplification. This statement should help team members understand the relationship of the impact of the hearing loss as it relates to language and speech. For example, the audiologist

may write something similar to the following for a severe hearing loss:

Without amplification, this child cannot hear soft sounds or normal conversational speech. Speech and

language will not develop without intervention. This child will benefit from early intervention with the use of appropriately fit amplification by a pediatric audiologist and special educational services that includes the Early Childhood Intervention (ECI) program.

R Recommendations

Recommendations should be consistent with the test findings. Follow-up appointments should be indicated with a specific timeline of services. Whenever possible, appointment dates and locations should be indicated. If additional hearing testing is necessary, scheduled appointments should coincide as closely as possible with the 1-3-6 guidelines. Referrals to the appropriate medical/educational facilities (EHDI team members) should be designed to meet the unique needs of the infant or toddler and family. The referral name of the early intervention coordinator/agency should be listed in the report. Recommendations should also be addressed for the Individualized Family Service Plan (IFSP) and may need to be addressed in a separate report (see *Appendix B*).

Conclusion

Connecting families to the EHDI process is critical for infants to receive optimal linguistic and communicative outcomes. Audiologists have a key role providing a seamless progression of care in the EHDI process. They connect families by:

- Providing or supervising timely follow-up screening for infants who fail newborn hearing screenings.
- Identifying a pediatric audiologist who has the appropriate training and audiological equipment necessary for testing. Wherever possible, the infant should be referred to a pediatric “Center of Excellence.”



Photo courtesy of NCHAM

For years, audiologists have strived to identify hearing loss in infants as early as possible, so that optimal access to speech and language could be provided.

- Performing ALL audiological tests necessary for an appropriate diagnosis of hearing loss in an infant using the Cross Check Principle.
- Writing a clear and concise report.
- Working actively to ensure infants are assessed, diagnosed, fit with amplification, and referred to the EHDI team in a timely manner consistent with the profession's standard of care.
- Educating families and team members using a multimedia approach concerning EHDI and audiological testing for better communication among all disciplines.
- Active participation in the existing (or implementing a comprehensive) information management system for program accountability and reduction of loss to follow-up.

For years, audiologists have strived to identify hearing loss in infants as early as possible, so that optimal access to speech and language could be provided. As this goal is now being realized, audiologists are overwhelmed with the numbers of babies who need help. Identifying key audiologists who can provide appropriate care within a community is just the first step the families with infants that have hearing loss must take. Infants with hearing loss and their families have a difficult road ahead of them. Audiologists have a professional responsibility to help infants and their families connect with state-of-the-art audiological, medical, and educational intervention services, as well as a moral obligation to make the road that families travel just a little easier.

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Appendix A

Web resources to help parents/professionals interpret acronyms:

EHDI Acronyms and Abbreviations (CDC, 2010)
cdc.gov/ncbddd/hearingloss/abrev.html

Web resources to help parents/professionals understand hearing loss in infants:

Achieving Optimal Outcomes from EHDI (Yoshinaga-Itano, 2011)
asha.org/Publications/leader/2011/110920/Achieving-Optimal-Outcomes-From-EHDI.htm

Centers for Disease Control and Prevention: Early Hearing Detection and Intervention (CDC, 2011b)
<http://www.cdc.gov/ncbddd/hearingloss/index.html>

Hands & Voices (2005)
<http://www.handsandvoices.org/>

How's Your Hearing
<http://www.howsyourhearing.org/>

Infant Hearing Guide (NCHAM, 2012)
<http://www.infanthearing.org/slideshow/ihg/index.html>

Joint Committee for Infant Hearing
<http://www.jcih.org/history.htm>

Marion Downs National Center
<http://www.mariondowns.com/>

My Baby's Hearing (2012)
<http://www.babyhearing.org/>

National Center for Hearing Assessment and Management
<http://www.infanthearing.org/>

Materials available for physicians:

AAP Teleconferences
infanthearing.org/medicalhome/aapteconference/index.html

National Center for Medical Home Implementation (2012)
http://www.medicalhomeinfo.org/how/clinical_care/hearing_screening/

Physician Education Materials
<http://www.infanthearing.org/physicianeducation/index.html>

Sound Beginnings Video
<http://www.infanthearing.org/videos/>

Appendix B

Diagnostic Audiology Report Template



Case History

This section should include any pertinent medical information concerning the infant. This may include the following:

- Referral reasons for the diagnostic evaluation.
- Maturation age of the infant.
- Prenatal, perinatal, and postnatal complications, if indicated.
- Risk indicators, if indicated.
- Familial history of hearing loss, if indicated.

Diagnostic Audiological Exams

If sedation is used, indicate that in your report. If not, state the status of the infant (i.e., baby Jill was tested while in a natural sleep). This section should also include:

- Tympanometry for each ear with acoustic reflex results. (Be sure to state the use of high-frequency tympanometry, when appropriate.)
- Otoacoustic information for each ear (state whether you used distortion product or transient OAEs).
- Auditory Brainstem Response (ABR) testing:
 - Air click information.
 - Tone burst information (at least 500 Hz and 2000Hz, if possible).
 - Bone conduction test information, if indicated.
 - Latency values and interwave latency values should be stated as within normal limits, delayed, absent, etc. (refer to latency norms when analyzing results).
 - If steady-state evoked responses were obtained, report results in this section.

Summary of Audiological Results

This section should summarize test findings and your impressions of the infant's hearing status. If a complete test was not performed, the reason why should be stated.

Recommendations

This section should include your recommendations for this child either in paragraph form or by enumerating your points. You should include any medical follow-up recommended, including genetic counseling, medical intervention, or medical clearance. Be very specific regarding referral to early intervention; follow-up audiological testing with specific time periods; classroom recommendations, if applicable; etc.

