

NEWBORN HEARING SCREENING: LOST TO DOCUMENTED FOLLOW-UP CONSIDERATIONS FOR THE MEDICAL HOME



Since 2000, the percentage of newborns screened for hearing loss dramatically increased from 52% to 95%. However, almost half of the children who “do not pass”^{*} hearing screening tests lack a documented diagnosis. The infant’s primary care medical home provider plays an important role in ensuring that timely follow-up and the appropriate documentation of that follow-up occur. Without the active assistance of the medical home, the infant may be considered “lost” in the early hearing detection and intervention (EHDI) system, which undermines the potential benefits of newborn hearing screening. A “wait and see” approach is never appropriate.

An infant who does not pass his/her newborn hearing screening has a potential **developmental emergency!**

**Do not pass includes infants who have “failed” or missed the hearing screening or those who had an invalid, uninterpretable result.*

WHAT CAN A NEWBORN IDENTIFIED WITH POSSIBLE HEARING LOSS BE “LOST” TO?

Lost to follow-up: For infants who did not pass newborn hearing screening, “lost to follow-up” refers to a failure to receive the next step of treatment, be it rescreening or comprehensive audiologic evaluation.

Lost to documentation: Failure to report the results from hearing screening, rescreening, diagnostic services, and/or treatment services to the state EHDI program and the medical home. These data are needed for comprehensive surveillance and monitoring to ensure infants receive recommended services. Lost to documentation can mean:

- Hospital does not record and/or report results of first screening
- Hospital does not record and/or report results of second screening
- Audiologist does not report results
- Medical home provider does not record and or report the results of the rescreening

Lost to treatment: Failure for a child with an identified hearing loss to receive needed therapeutic services and failure for families to receive needed information to support decisions regarding treatment options.

WHAT IS THE MEDICAL HOME’S ROLE IN REDUCING THE PERCENTAGE OF INFANTS WHO DO NOT PASS THE NEWBORN HEARING SCREEN AND WHO ARE THEN CONSIDERED LOST TO DOCUMENTED FOLLOW-UP?

The following information outlines specific actions the medical home can take to reduce the percentage of infants who do not pass a newborn hearing screening who either do not receive follow-up care or for whom follow-up is not reported back to the state EHDI programs. *It is important to note that the actions outlined below are specific to reducing lost to documented follow-up. There are many more recommendations for providers for the overall EHDI process that are not listed here. For additional information, please see the [2007 Joint Committee on Infant Hearing Position Statement](#) and [EHDI Guidelines for Pediatric Medical Home Providers](#).*

PRACTICE CONSIDERATIONS

Medical homes should obtain, document, and discuss all screening results and risk factors** as follows:

- Confirm that initial newborn hearing screening results have been obtained for all infants as soon as results are available but no later than 1 month. If results are not received, obtain results from

the screening hospital or state EHDI program. Accuracy in reporting is improved when information is *received directly from the hospital rather than from a verbal report from family*.

- Ensure that all newborn hearing screening results are recorded in patient's chart.
- Review all hearing screening results (whether passed or not) and stress the importance of follow-up/monitoring with the family, because hearing loss can occur at any time (see Family Education section below).

It is also the role of the medical home to coordinate care of a child that has a "do not pass" screening result or for whom you cannot obtain the documented screening results following the steps below:

- For a child with a "do not pass" screening result
 - a) Confirm with family whether rescreening has occurred
 - b) If **yes**, obtain results of rescreening from either the hospital or audiologist that conducted rescreen. Discuss results with family and confirm rescreen results with state EHDI program within 48 hours of receiving results. It is important that medical home providers understand how to report results to their state EHDI program. See links to state programs below.
 - c) If **no** (including those babies for whom you cannot obtain results)

For practices that do not conduct rescreening, ensure that a rescreening is scheduled and completed by 1 month of age. The medical home should take the lead in scheduling it. Confirm rescreening results with state EHDI program within 48 hours of receiving results.

For practices that are able to perform a rescreening in the office for newborns who do not pass initial screening, communicate the results with the family, **AND** report results back to the state EHDI Program within 48 hours (refer to *AAP Guidelines for Rescreening in the Medical Home Following a "Do Not Pass" Newborn Hearing Screening*)

- For an infant for whom you cannot obtain the documented screening results by 1 month of age:
 - a) *For practices that do not screen in office*, the medical home needs to arrange hearing screening immediately and should obtain the results after the screening has been completed. Be sure to confirm results with state EHDI program within 48 hours of receiving results. It is important that medical home providers understand how to report results to their state EHDI program (see links to state programs below), and if screening is not passed, ensure that rescreening is scheduled and completed as quickly as possible. The medical home should take the lead in scheduling it. Confirm rescreening results with state EHDI program within 48 hours of receiving results.
 - b) *For practices that are able to perform a screening in the office*, communicate the results with the family, **AND** report results back to the state within 48 hours (refer to *AAP Guidelines for Rescreening in the Medical Home Following a "Do Not Pass" Newborn Hearing Screening*). If child fails first in-office screening, refer to qualified audiologist. **DO NOT** retest in office.

Medical homes should provide education and support to families by:

- Sharing information about hearing, speech, and language milestones using one of the following resources:
 - ✓ [AAP Bright Futures: Recommendations for Preventive Pediatric Health Care](#)
 - ✓ [Learn the Signs, Act Early](#)
- Assisting in arranging transportation and social service support for families, as needed. It is suggested that a dedicated staff person be assigned to assist with this step. It is recommended that the practice/staff develop a relationship with the state EHDI coordinator/program, because

the state has access to additional resources to assist families of which the practice may not be aware.

- Offering and providing culturally competent and health literate appropriate information to educate and support families, including referral to Hands & Voices, Family to Family Health Information Centers, or other parent support groups. A dedicated office staff person can assist in working with the state EHDI coordinator to get these resources in order for parents/families. (See *list of resources at end of document.*)
- Ensuring family is referred to local Part C early intervention Program (<http://www.nectac.org/contact/ptccoord.asp>).
- Encouraging families to sign a release of medical information/records to the primary care physician. This includes information from early intervention, audiologists, and all specialists. Having all information in the medical home improves care coordination. (*Sample release forms can be found at: <http://www.medicalhomeportal.org/living-with-child/transition-issues/birth-to-three>.)*)
- Reviewing JCIH risk factors (see glossary).

EARLY HEARING DETECTION AND INTERVENTION (EHDI) SYSTEM CONSIDERATIONS

Early Hearing Detection and Intervention (EHDI) systems are encouraged to work with local birth facilities to establish best methods for obtaining test results. The following may be of assistance:

- Almost every state/chapter has an AAP EHDI Pediatrician Champion that serves as an EHDI expert and resource. To get your Champion's contact information, visit: <http://medicalhomeinfo.org/downloads/pdfs/EHDIChapterChampionsRoster.pdf>.
- State EHDI Coordinators are also available to assist in ensuring that children with hearing loss have timely and appropriate services. They are a valuable resource and can assist with every step in the EHDI process. To contact your state coordinator, visit: <http://www.infanthearing.org/status/cnhs.html>

HELPFUL EHDI RESOURCES

Below is a list of helpful EHDI resources for provider and to share with parents/families:

- [American Academy of Pediatrics Early Hearing Detection and Intervention Program](#)
- [Family to Family Health Information Centers](#)
- [Boys Town National Research Hospital](#)
- [Hands and Voices](#)
- [National Center for Hearing Assessment and Management \(NCHAM\)](#)
- [National Association for the Deaf \(NAD\)](#)