

The State of Newborn Hearing Screening and EHDI

The goal of EHDI programs is to improve the quality of life for infants with hearing loss through early detection and connection with services and family support. Screening without appropriate follow-up is unproductive. The mission of the birth/screening facility is to identify those infants at risk for hearing loss and refer them for diagnostic follow-up. This responsibility includes education of the parents to best ensure that follow-up is completed in a timely manner, and documentation of results and referrals.

Statistically, approximately 2-3 out of every 1,000 infants are born with significant hearing loss. (Russ 2010). Based on the 2010 Idaho birth number of 23,000, as many as 69 infants this past year may have been born with hearing loss in Idaho; yet the number of infants with a confirmed and documented diagnosis of hearing loss was only 39.

Infants can be 'lost-to-follow up' at any stage in the EHDI system. "This loss-to-documentation/loss to follow-up threatens the success of the newborn hearing screening program." (National Initiative for Children's Health Quality-NICHQ 2011)

Two major challenges to EHDI programs in reducing 'loss-to-follow-up' are:

- 1) Reducing the number of infants who are lost between the first screen and any follow up rescreen, and
- 2) Increasing the number of infants completing audiologic testing. (**56% in 2010**)

AAP and Joint Committee on Infant Hearing Guidelines:

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| a) "... hearing screening [completed] by | ① Month |
| b) audiologic and medical evaluation to ascertain the presence, type, and severity of the condition [completed] by | ③ Months |
| c) habilitation, treatment, or therapy for those individuals who are found to have the condition" | ⑥ Months |
| d) An effective statewide electronic tracking and monitoring system.
(American Academy of Pediatrics; JCIH 2007; Newborn Screening Systems: The Complete Perspective 2010) | |

Newborn Hearing Screening – Best Practice

A screening is a type of test designed to identify a population at risk and in need of further testing.

A hearing screen is a pass/refer type of test designed to identify newborns who require additional audiologic assessment in order to rule out or confirm the presence of hearing loss. **2-4%** of infants screened are expected to refer for comprehensive testing from NHS programs, slightly more if Otoacoustic Emissions are used.

Two-stage screening protocols are recommended in order to minimize the 'refer for diagnostics' rate, i.e. infants who do not pass their first screening should be rescreened before referral for audiologic testing.

Recommended AABR Screening Protocol:

Two good screenings* in the hospital; repeating both ears even if only one ear did not pass. Referral for frequency specific ABR to a *pediatric* audiologist if baby does not pass.

NICU: ONLY AABR screening should be used; if baby does not pass – direct referral to pediatric audiologist should be made; no outpatient screening should be performed.

Recommended OAE Screening Protocol:

Two good screenings should be completed. OAE programs are responsible for ensuring that necessary rescreening is completed within two weeks of discharge. A protocol should be in place to ensure that infants are not "lost" at this stage, including referral to Idaho Sound Beginnings-EHDI if infant is not rescreened within two weeks of discharge.

(Both ears must pass to be considered a "pass" result. Unilateral hearing loss can negatively impact speech development, and can sometimes develop into a bilateral loss.)

(*example-attempting to screen a crying, active baby rarely results in a 'good screening')

Components of a Model Hospital Screening Program:

1) Hearing Screening Coordinator

Every program should have a Coordinator responsible for overseeing all aspects of the Newborn Hearing Screening program including at a minimum:

- operation of a universal newborn hearing screening program including documentation of all live births and the screening status of each baby.
- completion and distribution of the ISB Referral Form for all ‘Refer’ and ‘High Risk’ babies.
- oversight of the data manager/data management process for EHDI.
- transmission of hearing screen results to the ISB- EHDI program and child’s primary care provider (PCP).
- provision of regular training to all screening and discharge personnel.
- oversight of parent education training including the use of scripts, procedures for communicating results, etc.
- annual calibration and upkeep of screening equipment including documentation of calibrations.

2) Education/Communication

Staff must be adequately trained and comfortable in providing correct information to parents. Parents who understand the reasons for NHS and early identification are more likely to follow-up with recommended care.

When communicating results.....	<p>? “What is the likelihood of <i>this</i> baby receiving audiologic follow-up by 3 months of age” ?</p> <p>Do parents understand: Where, When, Why, Who, and How to get more information?</p> <p>Might these parents need assistance with follow-up – sooner rather than later?</p>
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- Include education on NHS in pre-natal courses and prior to the screening.
- Inform parents that their newborn will have a hearing screen as part of the standard of care.
- Emphasize the importance of newborn hearing screening and **early** identification of hearing loss to parents. Clearly convey its impact on speech, language, social, emotional, and cognitive development.
- Communicate to parents the importance of auditory stimulation to Brain Development!
- Explain all results, including the difference between a ‘screen’ and a ‘diagnostic test’, and tell parent what the “Next Steps” are before they are discharged.
- Provide parent with ‘clear’ follow-up information i.e. contact information for pediatric audiologist and ISB; and “What Do I Do Now” brochure and completed ISB Referral Form
- Deliver information in a semi-scripted manner
- Provide information in family’s native language and in a culturally sensitive manner.
- Provide information in a written and verbal form.
- Use a checklist or some other method to document completion of referral and education process.

Making the audiology appointment for the family before discharge has been proven to reduce the “loss-to-follow-up” rate. If an appointment cannot be made, ensure that the audiologist’s name and contact information are written on the Referral Form. Distribute the form to: PCP, Audiologist, ISB-EHDI, and family.

3) Documentation is Vital “If it isn’t documented, it didn’t happen”

- Document all live births in tracking system
- Create a record for every infant born or transferred into the hospital.
- Provide contact information for all infants who may need follow up including missed babies.
- Enter all births daily into screening equipment to ensure no babies are missed and all births and transfers (in and out of facility) are accounted for.
- Establish a procedure and mechanism for quickly contacting and tracking families of babies that have been missed or need further screening (complete follow-up within 2 weeks of discharge).

- Document all hearing screening and incomplete results in pediatrician (PCP's) chart. Faxing refer results to PCP is highly recommended.
- **Transfers:** Indicate as a 'transfer' in HiTrack and include name of Receiving Hospital, Risks, Parent Contact information and PCP. An ISB Referral form may also be used to transmit this information.
- (Note: a very high percentage of transferred babies are at risk for late onset hearing losses and will require close monitoring. Include babies who are transferred out of state.)

Notes:

A large number of infants are lost to follow-up during the "Return for Rescreen/Outpatient" stage.

Completing the ISB Referral Form **prior to discharge** for all hearing screen refers and/or whenever risk indicators are present, is a simple yet efficient way to ensure that follow-up can be continued for those babies who are at a higher risk for hearing loss - infants who have not passed their initial screen are now at a higher risk for hearing loss than those who have not had a hearing screen (rate increases to 1-3 per 100).

Complete AABR two-stage screening before discharge. This greatly reduces the chance of an infant being "lost".

Over 40% of infants who refer are never documented to have completed audiologic follow-up. Parent education (using scripted messages), physician notification, prompt and correct documentation and reporting to ISB (EHDI) are proven methods that are shown to increase follow-up rate.

Parents aren't "hearing" much of what is said at discharge. Make sure to deliver any refer or risk results in a clear semi-scripted manner, in both written and verbal form, and with clear follow-up instructions.

The birth facility is responsible for reporting of the following electronic (Hi-Track) data elements:

All live births

All screening results (most will transfer automatically from the screening equipment),

- Missed screens and the reason for the missed screen if known (If all births are entered into screener daily, infants are less likely to be "missed")
- Inconclusive
- Refused
- Transferred (see note above)

Data Essentials - required data fields for all infants are:

- **Medical Record#, DOB, and Name – usually entered by the screener**
- Birth Facility, and Screening Site – normally set to auto-fill by the Coordinator during initial setup
- Screening Results (* including 'missed', 'transferred' 'refused' etc.)
- Baby's Primary Care Physician (PCP) or Clinic †
- *Contact follow-up information for babies who Refer or are Missed or Transferred (ISB staff can complete this information in HiTrack using the completed ISB Referral Form.) ***

* Not all screening equipment has the capacity to enter this information. Information such as: missed or transferred may have to be entered directly into the HiTrack record by the Data Manager.

** If no Referral Form was completed, hospital data manager should enter contact and PCP information directly into HiTrack record before transmitting data to ISB-EHDI. If needed contact information is missing, ISB-EHDI staff will request information from the Data Manager.

The Data Manager is responsible for reviewing the data in HiTrack for missed babies, duplicate records, peculiar MR#s, and other data discrepancies before transferring encrypted data to the state EHDI program.

Export of data from the screener into HiTrack should be done on a regular, timely (at least weekly) schedule in order to efficiently review data and "catch" missed babies before they become "lost."

Data should be transmitted to the State EHDI program by the 10th and 25th of each month. (Hospitals with less than 200 births per year should transmit data at least monthly, by the 25th of each month.)

Completing the ISB-EHDI Referral Form:

- Initiate the Referral Form and obtain the parent's signature at the time of the initial refer or when a risk indicator is first noted. (In the event that infant does not return for rescreen.)
- Include baby's medical record number to facilitate the tracking and ensure that the child's HiTrack record can be identified.
- Include the baby's Primary Care Provider (PCP) information and the parent contact information.
- Include an alternate contact number for the parent/caregivers.
- Document all risk indicators †
- Document results of all screens
- Include Audiologist referral and contact information on Form for all 'Refers.'
- Distribute forms (To- the PCP, audiologist, ISB-EHDI, and family) within
 - 5 working days if infant Refers when rescreen is completed at discharge, or
 - 2 weeks if infant does not return for rescreen appointment.

Note:

† Risk Indicators: ISB-EHDI sends a High Risk checkup reminder letter to parents when baby is approximately 8 months of age (for most risk factors), including a listing of Pediatric Audiologists and the "Hearing Milestones Checklist".

Maintenance and Equipment

Calibration, service and maintenance of the testing equipment should be followed as directed by the manufacturer, or no less often than yearly. Maintenance and service records should be maintained and be available for review by the consulting pediatric audiologist.

Don't "over screen" (the purpose is not to help the baby 'pass' the screen; it's to identify those babies at highest risk for permanent hearing loss).

Don't tell parents it's probably only fluid in the ears. This can be devastating if parent later finds out that there is a hearing loss.

Don't tell parents your equipment is faulty or not working (if you think this is true, call ISB (EHDI) and your equipment manufacturer immediately). [Loaner equipment is available at no cost from ISB]

Don't forget to complete the ISB-EHDI Referral Form before discharge, even if baby is scheduled for a follow-up screen.

Don't forget to send/fax copy of Referral Form to ISB (EHDI) within 5 days of refer or no follow-up.

Contact Idaho Sound Beginnings-EHDI at: 208-334-0829 - IdahoSoundBeginnings@dhw.idaho.gov

All Electronic Health Information shared with Idaho Sound Beginnings-EHDI as a public health entity is used for parent contact and assistance purposes only. If a signed ISB-EHDI referral form is received, the EHDI program may, if needed for follow-up purposes only, exchange information with the baby's Primary Care Provider, Audiologist, and Early Intervention Program as needed.