

Tennessee Department of Health (TDH) Early Hearing Detection and Intervention (EHDI) Newborn Hearing Screening (NHS) and Tennessee Department of Education Tennessee Early Intervention System (TEIS)

Child Find Notification Protocols for Newborn Hearing Screening Follow-up

The purpose of these protocols is to provide standardized guidelines for the Department of Health, Newborn Hearing Screening Program (NHS) and the Department of Education, Tennessee Early Intervention System (TEIS) to coordinate tracking, follow-up and intervention services to infants identified to be in need of further hearing testing or identified with a hearing loss.

I. The Role of Birthing Hospital and Facilities

(Refer to Newborn Hearing Screening Manual - Hospital Protocols)

- A. Birthing hospitals and facilities will conduct hearing screening (not mandated) on newborns prior to discharge.
 - 1. Results are to be reported by the facility to the parent/family and to the Primary Care Provider (PCP).
 - a. Results are reported as "Pass" or "Refer" for further testing.
 - 2. Infants that do not pass the hospital hearing screen are to be referred for further testing. They may be given an appointment to return to the hospital for further testing.
 - 3. Infants that do not receive a hearing screening prior to discharge are instructed to obtain a hearing screening prior to one month of age. They may be advised to return to the birthing hospital, to the PCP or to a screening provider.
 - a. This is the FIRST notification to the parent/family and PCP
- B. Birthing hospitals will report the Newborn Hearing Screening (NHS) results to the State Laboratory on the blood spot form used for mandatory Newborn Genetic/Metabolic testing.
 - 1. The Newborn Hearing Only form may be submitted if the blood spot form has already been sent to the State laboratory.

II. The Role of the Tennessee Department of Health, Newborn Hearing Program:

(Refer to Newborn Hearing Screening Manual)

- A. The State Laboratory will perform the designated tests on the blood spots and report the results with-in 10 days of receiving the blood spots.
 - 1. Results are reported to the submitting hospital and to the PCP
 - 2. Hearing screening results, as reported by the hospital, will be included on the laboratory report (mailer).
 - 3. This is the SECOND notification to the PCP of a passed test or for the need for further testing.

- B. The NHS program will send a follow-up letter to the parent/family and to the PCP 14 days after the lab report (mailer).
 - 1. Both letters advise the parent/family and PCP of the need to obtain further testing.
 - 2. The letter includes the 1-800 number for Tennessee Early Intervention System (TEIS) as well as the district office address and phone number (based on county of residence).
 - 3. This is the THIRD notification to the PCP.
 - 4. This is the SECOND notification to the parent/family of the need for further testing
- C. The PCP is to contact the family regarding the need for further testing. The infant may be instructed to obtain a re-screen at the PCP office or diagnostic testing at an appropriate provider.
- D. The NHS program will send a **Notification** letter to TEIS, Child Find on newborns that have not had a follow-up screen or diagnostic test reported.
 - 1. The letter requests TEIS to contact the parent/family to assess if further hearing testing was completed.
 - 2. The Notification will be sent six (6) weeks from the date of the initial laboratory mailer.
 - 3. Contact by TEIS will be the THIRD notification to the family of the need for follow-up testing.
- E. The NHS program will document follow-up results submitted by the hospital, family, PCP, or audiology provider.
- F. Infants determined to have a hearing loss will be referred to TEIS and Children's Special Services (CSS).

III. The Role of TEIS Child Find for Newborn Hearing Notification

The notification process is to be conducted for infants that did not pass the hearing screening in the hospital. Please report Child Find Newborn Hearing tracking information on any infant, under the age of one year, that you may become aware of through other sources (such as SSI) that was "referred for further hearing testing" due to newborn screening.

Older infants or children referred to TEIS for a suspected hearing loss are to have TEIS Referral and Intake procedures completed.

- A. The **Notification** letter will be sent to TEIS on newborns that have not had follow-up hearing testing reported to the NHS program.
 - 1. The Notification will be sent six (6) weeks from the date of the initial laboratory mailer.
 - 2. Contact by TEIS will be the THIRD notification to the family of the need for follow-up testing.
 - 3. The Notification letter will list the newborn's Tennessee Department of Health Number (TDH#) by the infant's name. This ID number is assigned to individual infant by the lab and is to be used when communicating with the NHS program.
 - 4. The letter will include infant and mother's demographic information, the test hospital, the PCP and the test results.
 - 5. The Notification will be sent to the TEIS district office that corresponds to the infant's home address.

- B. Child find will contact the parent or PCP by phone within 5 working days after notification.
 - 1. If unable to contact by phone within 5 working days from the date of last telephone attempt, send a TEIS brochure and a letter to the parent.
 - 2. If no response after 5 working days after letter sent, notify TIPS, by phone or fax, to request a home visit attempt to locate family.
 - 3. TEIS will document the outcome of child find efforts, including outcome of TIPS child find efforts (5-10 days after TIPS notification) based on receipt of return notification letter from TIPS.
 - a. Continue protocol for infants that are successfully located.
 - b. Document lost to follow-up status in the Tracking Status section of the computer data system. (See VI-B-3 of this document)
- C. Determine if hearing re-screen and/or diagnostic testing has been completed.
 - 1. Testing Not Completed:
 - a. Advise parent of need to contact PCP as soon as possible.
 - b. Assist parent with locating a PCP and/or
 - c. Provide the parent the name of pediatric hearing providers in the area.
 - 2. Testing Completed:
 - a. Passed:

Results may be reported in one of the following manners:

- i. Reported by parent as a passed re-screen at hospital prior to discharge. (Written confirmation not required.)
- ii. Reported by PCP as passed re-screen at hospital. (Written Confirmation not required.)
- iii. Reported by parent or PCP passed but infant at high risk for hearing loss to be followed in 3-6 months. (Request PCP to fax the Confirmation of Testing form with results to the NHS program or to TEIS program.)
- iv. Reported by PCP as passed in PCP office or audiologist office. (Request PCP to fax the Confirmation of Testing form with results to TEIS or the NHS program.)
- v. Fax Confirmation of Hearing Testing form to NHS program. If PCP faxes to NHS, TEIS will be notified.
- vi. Complete Child Find Tracking data entry.
- vii. Close to follow-up.
- b. Referred:

Referral for further testing or confirmed hearing loss may be reported in one of the following manners:

- i. Reported by parent as confirmed hearing loss.
- ii. Reported by parent as passed, suspect or pending until further tests complete.
- iii. Reported by PCP, audiologist or other medical provider as confirmed hearing loss.
- iv. Reported by PCP, audiologist or other medical provider as passed, no further testing indicated.
- v. Reported by PCP, audiologist or other medical provider as suspect or undetermined.
- vi. NOTE: Request the provider to fax the Confirmation of Testing form with results to TEIS or to the NHS program. (If PCP faxes to NHS, TEIS will be notified.)
- vii. Make referral (with parent consent) to TEIS, TIPS, and CSS.

viii. Offer parent support by referral (Parent's Encouraging Parents [PEP], Family Voices, etc.)

IV. The Role of TEIS in Newborn Hearing Loss Follow-Up

- A. Complete Referral and Intake Procedures
 - 1. Upon receipt of the referral, the TEIS office shall:
 - a. Appoint a service coordinator as soon as possible
 - b. Ensure that initial attempts by service coordinator to contact family of infant/toddler be made by phone or in person within 5 working days after receipt of referral into the early intervention system.
 - 2. Initial contact with family, the incoming service coordinator shall:
 - a. Explain the scope of early intervention services.
 - b. Discuss procedural safeguards.
 - c. Request parental consent for completion of multidisciplinary evaluation(s) and/or assessments.
 - d. Coordinate the multidisciplinary evaluation and assessment activities prior to the IFSP meeting (SBE 0520-1-10.02)
- B. Determine Eligibility

1. A child, from birth through age two, who is eligible for early intervention services because he or she has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, i.e. known, obvious, or diagnosable conditions such as sensory losses and severe physical impairments. Examples include, but are not limited to:

- a. Hearing loss which can be verified or estimated to be significant as indicated through audiological evaluation. (SBE 0520-1-10.02)
- b. The incoming service coordinator is responsible for oversight of evaluations to determine eligibility.
- c. The child's period of eligibility for services begins when documentation of the child's eligibility is completed by the incoming service coordinator and the multidisciplinary team. (SBE 0520-1-10.02)
- C. Development of Individualized Family Service Plan (IFSP)
 - 1. An Individualized Family Service Plan (IFSP) shall be developed and implemented for each infant or toddler birth to age three who is determined to be eligible for services under Part C and TEIS. (SBE 0520-1-10.02)
 - 2. The service coordinator shall communicate with the family and other IFSP team members in making arrangements for the IFSP meeting. (SBE 0520-1-10.02)

V. The Role of Tennessee Infant Parent Services in Newborn Hearing Loss:

The Tennessee Infant Parent Services (TIPS) role in the newborn hearing notification process:

- Will attempt to locate the family.
- Provide the parent the name of pediatric hearing providers in the area.
- TIPS will encourage the family to contact TEIS to complete tracking and followup protocols.

- A. TEIS will Notify the TIPS office if unable to contact the infant's family.
 - 1. A letter from TEIS requesting TIPS to continue child find efforts will be faxed to the district TIPS office.
 - 2. A copy of the infant's initial Notification letter will be faxed to the district TIPS office.
- B. TIPS Parent Advisors will make a home visit in an attempt to locate families with-in 5-10 working days from the date notified by TEIS.
- C. TIPS will provide the infant's family with information in regard to the importance of follow-up and provide information on how to contact TEIS to obtain further hearing testing and the names of pediatric hearing providers in the area.
- D. TIPS will report the outcome (successful or unsuccessful) of the home visit to TEIS.
- E. TIPS Parent Advisors will provide consultation and materials to TEIS Service Coordinators for staff and for parents (talking with parents about hearing loss, interpretation of diagnostic testing, etc.)

The TIPS role as a service provider:

- The TIPS Parent Advisor's primary goal is to support the parent in communicating with their baby and to encourage their baby's development through natural daily routine.
- Parent Advisors provide support and resources as families work to cope with and to understand the diagnosis of hearing loss through weekly home visits.

VI. TEIS Child Find Hearing Computer Tracking System:

- A. The computer tracking system will document newborn hearing screening follow-up by TEIS personnel. Personnel will be determined by each district office.
 - 1. The system was developed in cooperation with the TEIS Technical Support team at East Tennessee State University and the Tennessee Department of Health, Bureau of Informatics.
 - 2. The TEIS Quantitative Data System was expanded to capture minimum data sets requested for epidemiological Public Health purposes by the TN Department of Health and the Centers for Disease Control and Prevention (CDC)
 - 3. Documentation will be conducted on all infants contacted for follow-up and on all infants diagnosed with a hearing loss.
 - 4. The TEIS Child Find/Service Coordinator or designated data entry staff will conduct documentation.
- B. Data Entry
 - 1. Child Find Newborn Hearing Notification and Tracking
 - a. Notification Activities
 - i. TEIS Notification date TEIS notified by NHS program
 - ii. TEIS Brochure Sent date TEIS letter and brochure mailed to family
 - iii. TEIS/Parent Direct Contact date TEIS successfully made direct contact with family
 - iv. Audiological Results Received date results of hearing testing reported or received
 - b. Notification Tracking Status
 - i. TIPS Follow-Up Notification (date TEIS sent Notification to TIPS)
 - a. Indicate yes/no
 - b. Enter date TIPS contacted
 - ii. TEIS Lost to Follow-Up (date TEIS received message from TIPS of an

unsuccessful attempt to contact family)

- a. Indicate yes/no
- b. Enter date of closure to TEIS notification
- iii. Refused further hearing follow-up (TEIS notified by family of plan not to pursue further hearing screening or testing)
 - a. Indicate yes or no
 - b. Enter date
- 2. Hearing Diagnosis

Complete the following information for the right ear and left ear.

- a. Method(s) of Evaluation (drop down menu)
 - i. ABR Audiotory brainstem response
 - ii. OAE Otoacoustic Emissions
 - iii. TPOAE Transient Evoked Otoacoustic Emissions
 - iv. DPOAE Distortion Product Otoacoustic Emissions
 - v. TYMP Tympanometry
 - vi. ASSR Auditory Steady State Response
 - vii. BT Behavioral Testing (behavior observation audiometry, visual
 - reinforcement audiometry, conditional play audiometry)
- b. Degree of Hearing Loss (drop down menu) (divisions as requested by CDC)
 - i. WNL Within normal limits
 - ii. Mild (<=40 dB)
 - iii. Moderate (41-60 dB)
 - iv. Severe (61-80 dB)
 - v. Profound (>80 dB)
 - vi. Undetermined
- c. Type of Hearing Loss (drop down menu) (divisions as requested by CDC)
 - i. WNL Within normal limits
 - ii. Fluctuating Conductive
 - iii. Permanent Conductive
 - iv. Sensorineural
 - v. Mixed
 - vi. Unspecified (Auditory-Neuropathy)
- d. Date of Diagnosis
 - i. Record date of confirmed hearing loss
- e. Diagnosed by:
 - i. Record name and city
 - ii. Indicate yes/no
 - iii. Enter date decision reported by family
- 3. Referral Actions Taken
 - a. TEIS Intake TEIS Referral Intake (notification information screen will link to Intake Screen on infants found to have a hearing loss)
 - b. Family Parent Guide TEIS provided parent a packet of hearing related information (packet to be prepared by NHS program)
 - c. CSS Referral TEIS referred to CSS for enrollment evaluation
 - d. TIPS Referral TEIS referred to TIPS for early intervention services
 - e. IFSP Signed IFSP signed by family

- f. Mark Yes or No in the appropriate space for each activity
 - i. Not all activities will apply to each child
 - g. Record the date completed for each activity. Record date as month/day/yy. It is not necessary to have two digits for the month or day.
 - i. Not all activities will be completed on the same date.
 - h. The system will calculate the age by the number of days from birth for each activity

4. Providers/Services

- a. Specific Providers: Primary Care Provider, Medical Specialist (such as ENT), Genetic Provider, Audiology Provider
 - i. Indicate date the infant was first seen by specific provider
 - ii. Indicate the provider name and phone number
 - iii. Age at time of services will be calculated by the system by days from birth.
- b. Intervention Services

A drop down menu will list 17 early intervention service options:

- Assistive technology
- Audiology
- Family training/counseling
- Health Services
- Medical (Diagnostic Purposes)
- Nursing
- Nutrition
- Occupational therapy
- Physical therapy

- Psychological
- Respite
- Social Work
- Special Instruction
- Speech/Language
- Transportation
- Vision
- Other EI services
- i. Indicate type of each intervention service utilized by child
- ii. Indicate date the service started
- iii. Indicate the provider name and city
- iv. Age at time of service will be calculated by system by days from birth.
- 5. Hearing Devices
 - a. Hearing Aids
 - i. Indicate yes or no for each ear
 - ii. Enter initial hearing aid fitting date
 - b. Cochlear Implant
 - i. Indicate yes or no for each ear
 - ii. Indicate the date the cochlear implant surgery was completed
 - c. FM system
 - i. Indicate yes or no
 - d. Other

i. Indicate yes or no

- 6. Communication Methods
 - a. Indicate the communication method or methods chosen by the family communication
 - i. ASL American Sign Language
 - ii. SC Simultaneous (Total) Communication (Signed English)
 - iii. AO Auditory Oral

- iv. AV Auditory Verbal
- v. CS Cued Speech
- vi. Other (Bilingual Approach, BiBi)
- 7. Language Skills Status

Report the Combined/Total score if the receptive and expressive scores are not available. Results reported are not limited to a specific evaluation tool.

- a. One year (time of annual IFSP evaluation)
 - i. Receptive Language Age
 - ii. Expressive Language Age
 - iii. Combined or Total Language Age
- b. Two year (time of annual IFSP evaluation)
 - i. Receptive Language Age
 - ii. Expressive Language Age
 - iii. Combined or Total Language Age
- c. Three year (time of the three-year-old IFSP transition evaluation)
 - i. Receptive Language Age
 - ii. Expressive Language Age
 - iii. Combined or Total Language Age
- C. Data Reports/Access to Data
 - 1. The Department of Health Newborn Hearing program will provide a list of infants in need of notification on a quarterly basis. The list will be a comprehensive list of the infants in need of follow-up results and can be used as a quality assurance tool by TEIS.
- D. Resources
 - 1. Tennessee Department of Health Newborn Hearing Screening manual

2. Rules of Tennessee Department of Health, Health Services Administration, Maternal and Child Health, Newborn Screening Chapter 1200-15-1, Phenylketonuria. Hypothyroidism, and Other Metabolic/Genetic Defects (Section 1200-15-1.06 Department of Education and Department of Health Responsibilities – Hearing Screening)

3. IDEA Interagency Agreement – November 1, 2000

4. Early Hearing Detection and Intervention Program Guidance Manual, Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), February 2003.