

EARLY HEARING DETECTION AND INTERVENTION SYSTEM ELEMENTS

The Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program strives to fulfill the four purposes of the Infant Hearing Act (Neb. Rev. Stat. §71-4735):

- “To provide early detection of hearing loss in newborns at the birthing facility, or as soon after birth as possible for those children born outside of a birthing facility;
- to enable these children and their families and other caregivers to obtain needed multidisciplinary evaluation, treatment, and intervention services at the earliest opportunity;
- to prevent or mitigate the developmental delays and academic failures associated with late detection of hearing loss; and
- to provide the state with the information necessary to effectively plan, establish, and evaluate a comprehensive system for the identification of newborns and infants who have a hearing loss.”

Newborn hearing screening is one aspect of a comprehensive, integrated Early Hearing Detection and Intervention (EHDI) system. The elements of a comprehensive system are outlined by the eight principles of the Joint Committee on Infant Hearing’s Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs.

1. All infants should have access to hearing screening using a physiologic measure no later than one month of age.
2. All infants who do not pass the initial hearing screening and the subsequent rescreening should have appropriate audiologic and medical evaluations to confirm the presence of hearing loss no later than three months of age.
3. All infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis but no later than six months of age. A simplified, single point of entry into an intervention system appropriate for children with hearing loss is optimal.
4. The EHDI system should be family centered with infant and family rights and privacy guaranteed through informed choice, shared decision making, and parental consent in accordance with state and federal guidelines. Families should have access to information about all intervention and treatment options and counseling regarding hearing loss.
5. The child and family should have immediate access to high-quality technology, including hearing aids, cochlear implants, and other assistive devices when appropriate.
6. All infants and children should be monitored for hearing loss in the medical home (AAP Task Force, 2003). Continued assessment of communication development should be provided by appropriate professionals to all children with or without risk indicators for hearing loss.

7. Appropriate interdisciplinary intervention programs for infants with hearing loss and their families should be provided by professionals knowledgeable about childhood hearing loss. Intervention programs should recognize and build on strengths, informed choices, traditions, and cultural beliefs of the families.
8. Information systems should be designed and implemented to interface with electronic health records and should be used to measure outcomes and report the effectiveness of EHDI services at the patient, practice, community, state, and federal levels.

The screening, referral, and audiological evaluation protocols developed by the Advisory Committee of the Nebraska Newborn Hearing Screening Program, as it was known in 2001, are consistent with the first three principles of the Joint Committee on Infant Hearing (JCIH). The protocols are for hearing screening to be completed during birth admission, audiological diagnostic evaluation to begin prior to six weeks of age to minimize the need for sedation, and appropriate early intervention activities to be initiated by six months of age. The NE-EHDI Program continues to develop new approaches to create a comprehensive EHDI system as outlined in the JCIH principles.

The Early Hearing Detection and Intervention system in Nebraska is composed of five functional elements: Hearing Screening at Birth, Confirmatory Testing, Medical Evaluation, Early Intervention, and Tracking and Surveillance. One or more groups of professionals in a variety of settings assume responsibility of each element of the system. An overview of each of the elements and the primary activities are presented below. Included in this discussion are the Nebraska Revised Statute citations and the recommended protocols established by the Department of Health and Human Services through the Nebraska Early Hearing Detection and Intervention Advisory Committee.

Hearing Screening at Birth

Birthing facilities in Nebraska have five primary activities related to screening the hearing of newborns:

1. The parent(s) of newborns are educated about the hearing screening, the likelihood of hearing loss in newborns, the importance of follow-up, community resources (including early intervention services), and normal auditory, speech and language development (Neb. Rev. Stat. §71-4740). If risk factors are present, hospital personnel educate parents to evaluate hearing every six months. *Note:* The Department of Health and Human Services is responsible for educating the parent(s) for newborns not born in a birthing facility (Neb. Rev. Stat. §71-4740).
2. A hearing screening test is part of each birthing facility's standard of care for newborns, effective 12/1/03 (Neb. Rev. Stat. §71-4742). Following hospital protocol for the procedure, each newborn's hearing in each ear is

3. A mechanism for compliance review is established for each birthing facility (Neb. Rev. Stat. §71-4742).
4. Results of the hearing screening for each newborn are reported electronically to the NE-EHDI Program and should be reported to the newborn's Primary Care Provider.
5. Annual reports are calculated, based on the electronic reports for each occurrent birth, that indicate the numbers of babies born in the birthing facility, recommended for screening, received screening during birth admission, passed screening, did not pass screening, and recommended for monitoring and follow-up (Neb. Rev. Stat. §71-4739).

Confirmatory Testing

Newborns who have referred for one or both ears on the inpatient hearing screening should receive an outpatient screening or an audiological diagnostic evaluation to confirm the presence of a hearing loss and to determine the type and degree of the hearing loss. The primary recommended activities that comprise the confirmatory testing component are:

1. An outpatient screening may be conducted within one to three weeks if the baby "refers" on the first screening. The outpatient screening for those that "refer" during birth admission may occur at the birthing facility or at a confirmatory testing facility.
2. If the infant "refers" on the outpatient screening, the testing should proceed immediately to a comprehensive diagnostic evaluation. This evaluation minimally includes measures of middle ear function (high frequency tympanometry), auditory sensitivity (air- and bone-conducted ABR), confirmatory measures (parent observations) and, depending upon the developmental age, behavioral audiological assessment (Visual Reinforcement Audiometry). Other measures may be included, as indicated.
3. Depending upon a variety of factors, referrals are made for further evaluation, diagnosis, treatment, and services. These referrals may be made to medical specialists and/or early intervention services.
4. Results of the initial and comprehensive audiological diagnostic evaluation are provided to the Primary Care Physician and NE-EHDI Program.
5. Annual reports are submitted to the NE-EHDI Program that indicate the number of newborns who return for follow-up testing, the number who do not have a hearing loss and the number who do have a hearing loss (Neb. Rev. Stat. §71-4739).

Medical Evaluation

The infant's Primary Care Provider (PCP) has the key role in the follow-up for those who "refer" on the initial hearing screening during the birth admission. Building on the concept of a Medical Home (Guidelines for Pediatric Medical Home Providers, American Academy of Pediatrics), the PCP has the primary role in identifying and accessing the medical and non-medical services needed to help children and their families achieve their maximum potential. The primary activities that comprise the medical element of the newborn hearing screening system are:

1. Birthing hospital notifies PCP of the newborn's hearing screening results.
2. PCP or designee per hospital procedure informs parents of hearing screening results and need for re-screening or audiologic evaluation.
3. NE-EHDI Program notifies PCP about the hearing screening status and need for follow-up evaluation for those that did not pass the inpatient hearing screening or were discharged without a screening.
4. PCP (or staff), hospital, or test provider schedules an appointment for an outpatient screening to be completed in one to three weeks and notifies parents.
5. Provider of outpatient screening notifies PCP and NE-EHDI Program of results.
6. PCP notifies NE-EHDI Program of outpatient hearing screening results.
7. If "refer," PCP makes referral for comprehensive diagnostic evaluation, educates parents about need for evaluation, and makes referral to Early Intervention services.
8. If hearing loss is confirmed, PCP or diagnostic evaluator refers newborn/infant for complete medical and/or neuro-sensory evaluation and Early Intervention Services.

Early Intervention

Early intervention is an individualized program of services and supports based on the needs of the individual and family. Part C of the Individuals with Disabilities Education Act (IDEA) authorizes the creation of early intervention programs for infants and toddlers with disabilities. In Nebraska, the Early Development Network (EDN) provides services coordination for eligible families to identify and link with needed services and to work with multiple providers to ensure that services are provided. The recommended practices for the primary early intervention activities within the EHDI system are:

1. Upon receiving a referral, the EDN Services Coordinator immediately contacts the appropriate school district to begin the MDT process.
2. The Services Coordinator contacts the parent(s)/guardians to explain the importance of having a teacher of the deaf involved early and to obtain support for an initial joint meeting with the family.

3. Upon receiving verbal permission from the parent, the Services Coordinator contacts the Regional Programs for Students Who are Deaf or Hard of Hearing. The Regional Program coordinator contacts the school district to determine the appropriate teacher of the deaf to attend the joint meeting with the family.
4. The NE-EHDI Program is included on the Authorization for Release of Information form.
5. If the family would like support from organizations for young children with hearing loss and their families, the following organizations may be included on the "Release of Information" form to allow the parents' contact information to be shared: Regional Programs for Students Who are Deaf or Hard of Hearing, PTI-NE, and/or Hands and Voices.
6. A NE-EHDI Health Portfolio/Resource Guide for parents is provided.

Tracking and Surveillance

The NE-EHDI Program is based on the requirements identified in the Infant Hearing Act (Neb. Rev. Stat. §71-4735 - §71-4744) and the NE-EHDI Advisory Committee's recommended protocols to "...determine and implement the most appropriate system...to track newborns and infants identified with a hearing loss" and "...to effectively plan and establish a comprehensive system of developmentally appropriate services for newborns and infants who have a potential hearing loss or who have been found to have a hearing loss and shall reduce the likelihood of associated disabling conditions" (Neb. Rev. Stat. §71-4737). Activities of the NE-EHDI Program include:

1. Develop, implement, and monitor statewide systems to track newborns with or at-risk of hearing loss (Neb. Rev. Stat. §71-4737) and adopt and promulgate rules and regulations to implement the Infant Hearing Act (Neb. Rev. Stat. §71-4742 and §71-4744).
2. Gather required data and generate annual reports (Neb. Rev. Stat. §71-4739 and §71-4741).
3. Establish guidelines for referral to early intervention services (Neb. Rev. Stat. §71-4743).
4. Educate parents with out-of-hospital births about newborn hearing screening (Neb. Rev. Stat. §71-4740).
5. Apply for all available federal funding to implement the Infant Hearing Act (Neb. Rev. Stat. §71-4738).