



The New York Early Hearing Detection and Intervention

Best Practice Guide



Department
of Health

Purpose of the Document

This Best Practice Guide is intended to support NY healthcare professionals who provide hearing screening, diagnosis and care for children who are deaf or hard of hearing (D/HH).

This document is intended to be used as a resource for birth hospitals and centers, audiology practices, pediatricians, and other healthcare professionals to ensure that all babies and parents in NY receive the best care and information from the time of initial hearing screening through the diagnosis of permanent hearing loss, and ultimately until receiving Early Intervention services.

The guide includes an overview of the New York Early Hearing Detection and Intervention (NY EHDI) program, the rules and responsibilities of the healthcare providers and the best practices associated with each step in the newborn hearing screening process. The last section of this document focuses on counseling, health literacy, and strategies to reduce health literacy barriers.

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Overview of the New York State Early Hearing Detection and Intervention (NY EHDI) Program

The NY EHDI Program aims to ensure that all infants receive a timely and accurate newborn hearing screening so that those with hearing loss can be identified and receive appropriate intervention, enabling each child to reach his or her full potential. The NY EHDI Program supports the national EHDI 1-3-6 goals in which:

- “1” - All infants are screened for hearing loss no later than 1 month of age, preferably before hospital discharge.
- “3” - All infants who do not pass the screening will have a diagnostic audiologic evaluation no later than 3 months of age.
- “6” - All infants with a hearing loss are enrolled in early intervention services no later than 6 months of age.

State Responsibilities

The New York Department of Health oversees the NY EHDI Program including:

- Management of surveillance system.
- Oversight of reporting requirements.
- Provide training and Technical Assistance.
- Provide advocacy for children and families.

Requirements of Infant Hearing Screening Program

It is necessary for all partners to complete their responsibilities within the EHDI Program in accordance with NY law and regulations and/or protocols developed by the state EHDI system to ensure that children with hearing loss are identified and enrolled in early intervention services in a timely manner.

Role of Birthing Facility

- **Share** educational materials and discuss the hearing screening process with parent(s) prior to screening. Education Brochures for families are available at: https://www.health.ny.gov/community/infants_children/early_intervention/newborn_hearing_screening/resources_for_parents/
- **Screen** newborns' hearing prior to discharge from the facility.
- **Communicate** screening results with the parent(s) and provide written materials consistent with the screening outcome. Talk with the parent(s) about the next steps if the child has risk factors.
- **Explain** the importance of a follow-up screening if the child does not pass the inpatient screening. Birth facility is required to inform the parent(s) that if results of a follow-up outpatient screening are not returned to the facility, the child will be referred as an at-risk child to the Early Intervention Official in their county of residence for follow-up purposes unless the parent(s) object to such a referral.
- **Notify** the primary health care provider about hearing screening results. Ensure the results are also documented in the child's discharge summary.
- **Schedule** outpatient follow-up for children who do not pass.
- **Follow** the child post discharge to confirm follow-up hearing screening or diagnostic audiologic evaluation was completed.
- **Document** hearing screening follow-up results in the EHDI-Information System (EHDI-IS).

Refer to county Early Intervention at-risk (Child Find) within 75 days if the child needs re-screening, and no hearing screening follow-up or diagnostic audiologic evaluation was conducted. The birth hospital is required to make two documented attempts to reach the family. If unsuccessful, please refer the child to EI at-risk (Child Find). A list of municipality/county contacts can be found at: https://www.health.ny.gov/community/infants_children/early_intervention/county_eip.htm.

Birthing Facility Best Practices¹

- **Standardize** the message given to the parent(s) when a child does not pass the initial screening test.
- **Collect** additional contact information for children who do not pass their screening. Get a second point of contact for the family (e.g., telephone number of a relative or friend). Document this contact information in the Electronic Health Records (EHR).
- **Verify** the identity of the Primary Care Provider (PCP)/Medical Home or clinic responsible for follow-up with both the parent(s) and assigned provider at the time the child is screened before the family leaves the hospital. Document the PCP in the EHR.
- **Schedule** a follow-up appointment (rescreening or diagnostic audiologic evaluation appointment) at the time that the child does not pass the screening—before the family leaves the hospital— and stress its importance.

Transferred Children

In-State Transfers: For children transferred from one birth facility to another such facility prior to completion of the hearing screening:

- The birth hospital must document the transfer in the EHDI-IS.
- The birth hospital must notify the receiving hospital of the status of the hearing screening.
- The facility discharging the child to home is responsible for completing the screening, arranging any necessary follow-up, and documenting all hearing screening results in the EHDI-IS.

Adoption or Foster Care: Newborns that will be placed for adoption will have the hearing screening and any repeat screenings conducted prior to discharge. If a referral for diagnostic follow-up is indicated, the follow-up information will be given to the representative of the adoption agency at the time the newborn is discharged, as well as to the birthing facility social worker and/or discharge planner, as per facility policy.

Non-Resident Births: Any child born in a New York birthing hospital should have the hearing screen conducted, regardless of the state of residence.

Out-of-State Births: For children transferred from a New York hospital to an out-of-state hospital and in the event the hearing screen has not been conducted prior to transfer due to the child's medical condition, screening still needs to occur. All states bordering New York State have hearing screening programs, and therefore, the hospital of transfer can conduct the hearing screening on the child prior to discharge. If the child did not receive newborn hearing screening before discharge, the medical home provider is responsible to ensure that screening is completed at no later than 1 month of age.

¹ Promising Practices to Reduce Loss to Follow up can be found at https://www.infanthearing.org/ehdi-ebook/2022_ebook/3%20Chapter3Tracking2022.pdf

Role of Audiologists

- **Complete** the diagnostic audiologic evaluation on children who do not pass their newborn hearing screening to confirm or rule out hearing loss.
- **Document** all hearing screening and evaluation results in the EHDI-IS (type of hearing loss, and severity for both ears).
- **Educate** families about the results of the hearing evaluation and what the results mean. Ensure the family is clear on the next steps.
- **Monitor** and evaluate children at risk for hearing loss. Use the recommendations provided in the Joint Committee on Infant Hearing (JCIH) 2019 statement table 1 to determine the next steps for children with risk factors for hearing loss. The JCIH 2019 recommendations are available at <http://www.jcih.org/posstatements.htm>.
- **Refer** children with hearing loss to the Early Intervention services within 2 days of the diagnosis.
- **Notify** the child's PCP of hearing screening and evaluation results.
- **Inform** the child's PCP if the child has missed the rescreening, diagnostic audiologic evaluation or the hearing aid fitting appointment.
- **Provide** information about hearing loss, unbiased communication options and resources to families. Audiologists should make sure families know all of their options and can help them begin the process of determining the best ways to communicate with their child.

Audiologists Best Practices

- **Call** the family before the diagnostic audiology appointment to confirm the appointment, time and place and include the reasons why the appointment is important. Offer assistance to help family get to the appointment, if necessary (e.g., transport vouchers).
- **Track** the follow-up visits very closely. You can make two audiology appointments when scheduling diagnostic audiologic evaluation, so that if the child cannot be completely evaluated at the first appointment scheduled, they can return within a reasonable timeframe. Cancel the second appointment, if not needed. Document the appointments in the EHR.
- **Alert** the PCP about the results and the need for follow-up. You can send the results using Electronic Health Records notes or a fax-back form.
- **Document** the procedures and results into the EHDI-IS promptly.

Role of Medical Homes/Primary Care providers²

- **Obtain** newborn hearing screen no later than 1 month of age if no hearing screening has been done in the birth hospital.
- **Assess** risk factor(s) associated with congenital hearing loss and/or late-onset or progressive hearing loss and stress follow-up/monitoring for risk factors. Please use the recommendations provided in the JCIH 2019 statement table 1 to determine the next steps for babies with risk factors for hearing loss. The JCIH 2019 recommendations are available at <http://www.jcih.org/posstatemts.htm>.
- **Refer** children who do not pass the hearing screening immediately to an audiologist for diagnostic audiologic evaluation.
- **Confirm** diagnostic audiology visit is scheduled and completed by no later than 3 months of age.
- **Ensure** that a diagnostic audiologic evaluation is completed for children who passed their birth-screen but are at risk for hearing loss.
- **Monitor** the developmental milestones, auditory skills, parental concerns, and middle ear status to assess need for further audiologic testing.
- **Elicit** whether there is parental concern about the child's hearing, and if the diagnostic audiology evaluation should be conducted.
- **Refer** to Part C Early Intervention Program, ophthalmology, ENT and offer genetics referral if hearing loss is confirmed.
- **Verify** entry into Early Intervention services no later than 6 months of age if hearing loss is confirmed.
- **Obtain** parental written informed consent for release of information at first contact with the EIP, in order for information to be shared between the EIP and the PCP.

Medical Homes/ Primary Care providers Best Practices

- **Get** results from diagnostic test facility directly as opposed to a verbal report from a parent(s)/ caregiver.
- **Assist** family in arranging follow-up appointment(s).
- **Encourage** prompt follow-up with re-screens and diagnostic audiologic evaluation.
- **Set up** electronic medical record (EMR) system to include results of auditory screening.
- **Flag** all patient charts for children that are at risk for late onset hearing loss or those who require follow-up for hearing screens.
- **Send** child to audiologist with pediatric expertise for diagnostic audiologic evaluation.

² Guidelines for Medical Home Providers for Reducing Loss to Follow-Up/Documentation in Newborn Hearing Screening are available at: <https://infantheating.org/medicalhome/docs/Algorithm-MedHome-Guidelines.pdf>

Communicating Results to Families

- **Communicate** screening results to the parent(s) immediately.
- **Explain** what the results mean in clear, non-technical terms and in the native language of the family (if applicable).
- **Use** proper terminology and do not downplay the outcomes of the testing, while balancing creating undue anxiety for the family.
- **Allow** enough time to discuss the results, explain the next step, and answer parent(s) questions.
- **Be** culturally sensitive. Avoid using terms or expressions that may be easily misinterpreted.
- **Provide** contact information to the family of one resource provider who can answer further questions after discharge.
- **Provide** parent(s) with written information in their native language regarding the necessity of the referral.
- **Explain** the possible impact of unidentified hearing loss.
- **Ask** the parent(s) to repeat instructions for follow-up care.

Hearing Screening Refusal

New York law states that all children born in New York must have their hearing screened. However, families do have the right to refuse the hearing test. **Remember to:**

- **Provide** the parent with information on newborn hearing screening. Parent(s) should be provided the “Can your Baby Hear you? Information for Parents” educational brochure.
- **Discuss** the risks and consequences of this choice with the parent(s) to make a fully informed decision.
- **Record** “refused” in the hearing screening section in EHDI-IS.
- **Maintain** written documentation of the parents’ refusal in the child’s medical file.
- **Notify** the PCP of parent refusal.

Health Literacy

The U.S. Department of Health and Human Services (HHS) addresses health literacy as central focus of Healthy People 2030 and defines the personal health literacy and organizational health literacy as the following:³

- **Personal Health Literacy:** the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment.
- **Organizational Health Literacy:** the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Health literacy is important to ensure that child's parent(s):

- Use health information rather than just understand it.
- Make "well-informed" decisions.

Health literacy is not limited only to the ability to read and write. There are other factors that affect how parent(s) obtain, process, and understand health information that they are told, see, hear, or read. The table below lists some factors associated with diversity and health literacy and their impact of early identification of hearing loss and adherence to follow-up.

Table 1: Factors associated with diversity and health literacy and their impact on newborn hearing screening and follow up.

Culture and Linguistic Factors: Cultural background and primary language may disrupt the process of navigating the health care systems to receive the specialized care necessary for achieving optimal outcomes for children with hearing loss.⁴

Examples:

- Familial structure and who should receive the hearing results.
- Family's readiness to accept a diagnosis of hearing impairment in a child.
- English-speaking audiologists and Limited English Proficient (LEP) Parents.

Impact:

- Acceptance of infant hearing loss.
- Timeliness of testing and diagnosis.
- Understanding complex medical information.
- Navigating the healthcare system to reach the necessary specialty care.
- Lack of communication or miscommunications with health care providers.
- Families misunderstanding or uncertainty.

³ The U.S. Department of Health and Human Services' Health Literacy definition can be found at: <https://health.gov/healthypeople/priority-areas/health-literacy-healthy-people-2030>

⁴ Holte, L., Walker, E., Oleson, J., Spratford, M., Moeller, M. P., Roush, P., ... & Tomblin, J. B. (2012). Factors influencing follow-up to newborn hearing screening for infants who are hard of hearing.

Socioeconomic Factors: Various socioeconomic factors are associated with delay in accessing hearing health care services, resulting in delayed hearing loss confirmation, delayed hearing aid fitting, and delayed enrollment in early intervention.^{5,6,7}

Examples:

- Parent(s) educational attainment.
- Difficulty getting transportation to and from appointments.
- Problems with insurance coverage and access to healthcare (e.g., difficulty finding a provider that will cover hearing aids; patients lack insurance).

Impact:

- Lack of knowledge about the importance of timely identification and intervention.
- Late initiation of follow up or difficulty with scheduling follow-up appointments.
- Difficulty getting transportation to and from appointments.
- Difficulty finding Medicaid providers that will cover hearing aids.

Coordination Across the Continuum of Care^{8,9}

Examples:

- Lack of communication between and among health care providers.
- Lack of provider time.
- Lack of knowledge surrounding 1-3-6 guidelines and best practices.
- Providers unable to access or share health information because of consent issues.

Impact:

- Mistrust of the healthcare system.
- Delays in initiation of follow-up or delays in receiving diagnostic audiologic evaluation and intervention services.
- Lack of follow-up of children at risk for progressive or late-onset hearing loss.
- Difficulty exchanging information between the EIP and the PCP or other healthcare providers.

⁵ Crouch, E. L. Probst, J. Bennett, K. J. & Carroll, T. (2017). Evaluating Loss to Follow-Up in Newborn Hearing Screening in a Southern State. *Journal of Early Hearing Detection and Intervention*, 2(1), 40-47. DOI: <https://doi.org/10.15142/T3T33Z>

⁶ Meyer AC, Marsolek M, Brown N, Coverstone K. Delayed Identification of Infants Who Are Deaf or Hard of Hearing — Minnesota, 2012–2016. *MMWR Morb Mortal Wkly Rep* 2020;69:303–306. DOI: <http://dx.doi.org/10.15585/mmwr.mm6911a6>

⁷ Cree RA, Bitsko R, Grimm C, et al. Provider Perspectives: Identification and Follow-up of Infants who Are Deaf or Hard of Hearing [published online ahead of print, 2022 Oct 28]. *Am J Perinatol*. 2022;10.1055/a-1932-9985. doi:10.1055/a-1932-9985

⁸ American Speech-Language-Hearing Association. (2008). Loss to follow-up in early hearing detection and intervention [Technical Report]. Available from www.asha.org/policy.

⁹ Tharpe, A. M. (2009). Closing the gap in EHDl follow-up. *The ASHA Leader*, 14(4), 12-14.

How to Reduce Barriers to Health Literacy?

1. Identify the red flags

- Frequently missing follow-up appointments.
- Parent(s) ask fewer questions.
- Lack of follow-through on tests or referrals.

2. Improve communication

- Use plain language.
- Avoid use of medical jargon.
- State information clearly and simply.
- Ensure parent(s) have enough time to ask questions.
- Use an interpreter if a patient requires one due to language or disability.
- Focus on “need to know” and ‘need to do’.
- Use written materials and other formats that are easily accessible when providing education about the importance of follow-up (e.g., fact sheets, podcasts, or online videos).

3. Deliver patient-centered care

- Be aware of health disparities and discrimination affecting various populations.
- Respect the distinctive nature of the family values, experiences, preferences, and expressed needs.
- Make patients aware of interpreter services and auxiliary aids.
- Provide unbiased information for communication options.
- Connect the parent(s) with support professionals and resources.

4. Learn more about Health Literacy

- CDC’s Health Literacy Basics: <https://www.cdc.gov/healthliteracy/learn/index.html>
- The American Speech-Language-Hearing Association (ASHA) Health Literacy Resources: https://www.asha.org/slp/health_lit_resources/
- The National Center for Hearing Assessment and Management (NCHAM) Resource Guide for Early Hearing Detection and Intervention: Chapter 17: Family Support & Cultural Competence: <https://www.infanthearing.org/ehdi-ebook/>
- Free course on Health Literacy from The American Academy of Pediatric free course: <https://shop.aap.org/health-literacy/>
- Nicholson, N. Rhoades, E. A. Glade, R. E. & Smith-Olinde, L. (2022). Impact of Social Determinants of Health on Early Hearing Detection and Intervention Screening/Diagnosis Outcomes. *Journal of Early Hearing Detection and Intervention*, 7(3), 16-34. DOI: <https://doi.org/10.26077/67f1-9670>

