Medical Home Providers: 
Chapter 2 & 3 
May 20, 2019 

Michaelah Townley, MPH 
NYEHDl Program Follow-up Coordinator, DOH 

Sharon Wu, MS 
NYEHDl Program Data Coordinator, DOH 

Jessica Holst, MS CCC-SLP 
NYEHDl Education and Training Contractor
NYEHDHI: Program Goals
CDC EHDI Goals

Goal 1: Screening before one month of age
Goal 2: Audiologic evaluation before 3 months of age
Goal 3: Early Intervention before 6 months of age
Goal 4: Late onset, progressive or acquired hearing loss identified at the earliest possible time
Goal 5: All infants with hearing loss will have a medical home
Goal 6: State EHDI tracking and surveillance system
Goal 7: Comprehensive monitoring system to evaluate state EHDI program
NYEHDl Program Goals

- 240,000 births annually at 124 birthing facilities across the state
- All infants born in a hospital will receive an inpatient screen (NICU and other exceptions exist) by **1 month of age**
- All infants who do not pass (refer) will receive a rescreen (follow-up) in one of the following places:
  - Birthing hospital
  - Birthing hospital outpatient audiology clinic
  - Private audiology practice
  - Physician office
- If an infant does not pass a re-screen, they should receive a diagnostic evaluation by **3 months of age**
- Appropriate interventions should be *in place* by **6 months of age**
NYEHDII:
Program History
NYEHDNI History

NYS Public Law requires any provider who conducts hearing testing on infants younger than 6 months of age to report results to the NYS Department of Health.
NYEHDHI: Program Components
Three Key Components of Early Hearing Detection & Intervention Programs

Birth Admission Screening

Follow-up Screen & Diagnostic

Early Intervention
NYEHDl Program Components:

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking & Data Management
Universal Newborn Hearing Screening

- Babies who do not pass their initial screening may be re-screened prior to discharge if feasible
  - A two-stage screening is recommended by the Joint Committee on Infant Hearing (JCIH).
- If re-screening prior to discharge is not feasible or passing results are not obtained, the baby will be referred for re-screening to take place after discharge
  - Parents of infants who do not pass following the inpatient screening **must be given a prescription for their baby to have an outpatient hearing screening**, either at the birth hospital or from a provider qualified to perform the screening in their community. The discharging hospital must **provide a list of qualified providers of infant hearing screening if the parents opt to pursue follow-up at a different facility**.
  - The prescription will include a request that **the results of the follow-up hearing screening be returned to the birth facility**.
Universal Newborn Hearing Screening

- Screening method: OAE vs AABR
  - Both screening methods are reliable and can be used separately or together based on:
    - If the baby needs intensive (ABR) or routine care (A-OAE and/or A-ABR)
    - Method is left up to the hospital’s choice
    - Follow State EHDI guidelines
  - Both A-OAE and A-ABR may miss very mild hearing loss and frequency-specific hearing loss
    - A-OAE will miss auditory nerve or brainstem pathway dysfunction, such as auditory neuropathy spectrum disorder
  - Babies screened for hearing with an A-ABR in the hospital and resulted in “do not pass” should not be rescreened in the office with an A-OAE and “passed”
Universal Newborn Hearing Screening

- Birthing hospital reporting responsibilities
  - All birthing hospitals are **required to submit individual level data through the birth certificate (vital records) to NYEHDI-IS**
  - Required data elements include:
    - Patient information (received from vital records)
      1. Name, DOB, sex, address
      2. Mother’s name, DOB, race, education, address, phone
      3. Father’s name, DOB, race, education, address, phone
      4. Or legal Guardian information
    - Screening type
      1. Initial screening
        a. NICU stay
        b. Data entry correction
      2. Follow-up screening
        a. Date conducted
        b. Screening results (left/right)
        c. Method used (ABR/OAE)
        d. Screener qualification
Universal Newborn Hearing Screening

○ Required data elements cont’d
  ■ Diagnostic Evaluation
    ● Severity of hearing loss (left/right)
    ● Configuration of hearing loss (left/right)
    ● Date conducted
  ■ Referral to County of Residence Early Intervention Program
    ● Referral to Early Intervention Child Find Program
    ● Referral for suspected hearing loss
    ● Referral for identified hearing loss
    ● Parental objection
    ● Date of referral (or parental objection) to Early Intervention
  ■ Amplification
    ● Date of amplification
    ● Amplification Type
  ■ Comments
  ■ Refusal of Screening
Universal Newborn Hearing Screening

- For those infants who "refer," facilities should also coordinate with professionals conducting outpatient screenings/diagnostic evaluations to ensure required reporting by evaluating entity into NYEHDI-IS
- If no follow-up results are received by the hospital after 75 days post-discharge, infants are to be referred as “at-risk” to the Early Intervention Official in their county of residence for follow-up purposes, unless the parent has objected to such a referral (Child Find)
NYEHD Program Components:

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking & Data Management
Medical Home (Primary Care)

- Role of the primary care provider:
  - Ensures appropriate and timely steps are taken to identify children who are Deaf/HH and get them into an early intervention program
  - Serves as the primary coordinating entity to help reduce loss to follow-up/documentation

- Primary care provider reporting responsibilities:
  - Confirm that the newborn hearing screening has been conducted
  - Which technique (A-OAE or A-ABR) was used
  - Screening results are reported to state EHDI program
  - Specialty referrals if appropriate

Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers

Newborn Screening Birth
- Identify a Medical Home for every infant
  - Hospital-based Inpatient Screening
    - OAE/AABR* (only AABR or ABR if NICU* 5+ days)
    - All results sent to Medical Home
  - No more than 2 screening attempts recommended prior to discharge

Screening Completed Before 1 Month
- Outpatient Re-Screening* (OAE/AABR*)
  - All results sent to Medical Home and State EHDI* Program

Diagnostic Evaluation Before 3 Months
- Pediatric Audiologic Evaluation* with Capacity to Perform:
  - OAE*
  - ABR*
  - Frequency-specific tone bursts
  - Air & bone conduction
  - Sedation capability (only needed for some infants)
  - Hearing Loss
    - Unilateral/Bilateral; Sensorineural/Conductive/Mixed; Mild/Moderate/Severe/Profound

Intervention Services Before 6 Months
- Continued enrollment in IDEA* Part C
  (transition to Part B at 3 years of age)
- Referrals by Medical Home for specialty evaluations, to determine etiology and identify related conditions:
  - Otolaryngologist (required)
  - Ophthalmologist (recommended)
  - Geneticist (recommended)
  - Developmental pediatrics, neurology, cardiology, nephrology (as needed)

Team Advises Family About:
- All communication options; different communication modes; assistive listening devices (hearing aids, cochlear implants, etc); parent support programs

Medical & Otologic Evaluations
- To recommend treatment and provide clearance for hearing aid fitting

Pediatric Audiology
- Hearing aid fitting and monitoring

Ongoing Care of All Infants*; Coordinated by the Medical Home Provider

*OAE = Otoacoustic Emissions, AABR = Automated Auditory Brainstem Response, ABR = Auditory Brainstem
Ongoing Care of All Infants\(^d\); Coordinated by the Medical Home Provider

- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Provide vision screening (and referral when indicated) as recommended in the AAP “Bright Futures Guidelines, 3rd Ed.”
- Provide ongoing developmental screening (and referral when indicated) per the AAP “Bright Futures Guidelines, 3rd Ed.”
- Refer promptly for audiology evaluation when there is any parental concern\(^f\) regarding hearing, speech, or language development
- Refer for audiology evaluation (at least once before age 30 months) infants who have any risk indicators for later-onset hearing loss:
  - Family history of permanent childhood hearing loss\(^d\)
  - Neonatal intensive care unit stay of more than 5 days duration, or any of the following (regardless of length of stay):
    - ECMO\(^d\), mechanically-assisted ventilation, ototoxic medications or loop diuretics, exchange transfusion for hyperbilirubinemia
    - In utero infections such as cytomegalovirus\(^d\), herpes, rubella, syphilis, and toxoplasmosis
    - Postnatal infections associated with hearing loss\(^d\), including bacterial and viral meningitis
    - Craniofacial anomalies, particularly those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies
    - Findings suggestive of a syndrome associated with hearing loss (Waardenburg, Alport, Jervell and Lange-Nielsen, Pendred)
    - Syndromes associated with progressive or delayed-onset hearing loss\(^d\) (neurofibromatosis, osteopetrosis, Usher Syndrome)
    - Neurodegenerative disorders (such as Hunter Syndrome) or sensory motor neuropathies (such as Friedreich’s ataxia and Charcot Marie Tooth disease)
    - Head trauma, especially basal skull/temporal bone fracture that requires hospitalization
    - Chemotherapy\(^d\)

\(^d\)Denotes risk indicators of greater concern. Earlier and/or more frequent referral should be considered.

Notes:
(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss (or loss to follow-up) also may be referred directly to Pediatric Audiology.
(b) Part C of IDEA\(^*\) may provide diagnostic audiologic evaluation services as part of Child Find activities.
(c) Even infants who fail screening in only one ear should be referred for further testing of both ears.
(d) Includes infants whose parents refused initial or follow-up hearing screening.


February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)
Ongoing Care of All Infants; Coordinated by the Medical Home Provider

- Refer promptly for audiology evaluation when there is any parental concern regarding hearing, speech, or language development
NYEHDII Program Components:

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking & Data Management
Diagnostic Audiology

- The diagnostic audiological evaluation should be performed by a NYS licensed audiologist
- Role of the licensed audiologist:
  - If diagnostic audiological assessment indicated, complete before 3 months of age
  - Perform as series of tests to determine:
    - If a hearing loss exists
    - Type
    - Degree
    - Configuration of the loss
- Audiologist reporting requirements:
  - Documents the results of diagnostic audiological assessment in NYEHDI-IS by 3 months
  - Refers infant to early intervention and family support, if appropriate
NYEHDPI Program Components:

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking & Data Management
Speciality Referrals

- **Otolaryngology (ENT)**
  - Assess integrity of ear canal and middle ear
  - Order appropriate diagnostic testing such as temporal bone CT or MRI
  - Discuss necessary surgical interventions
  - Counsel family and follow for success of intervention

- **Genetics**
  - Evaluate for possible genetic causes of hearing change
  - Counsel family and patient

- **Ophthalmology**
  - Assess integrity of visual system
  - Evaluate for visual problems known to be associated with hearing changes
NYEHDPI Program Components:

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking & Data Management
Early Intervention

- Early Intervention (EI) services are provided to children and families under the Individuals with Disabilities Education Act (IDEA) of 2004, Part C *
  - Non-Part C (NYS schools for the deaf)
- All families of infants who are deaf or hard of hearing, regardless of degree of hearing loss or whether it is one ear (unilateral) or both ears (bilateral), should be considered eligible for early intervention services
- Children identified as deaf or hard of hearing who begin services before 6 months old can develop language (spoken or signed) on a par with their hearing peers (Yoshinaga et al., 1998).
- Early Intervention provider/service coordinator requirements:
  - Conducts multidisciplinary evaluation and ensures timely enrollment by 6 months
NYEHDII Program Components:

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking & Data Management
NYEHDIP Program Components:

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking & Data Management
Patient Demographic Information Area

Last Name HOLST
First Name MOLLY
Middle Name ANN
ID # 9206055
Gender F
Birth Date 01-Aug-2013 (5 Years, 3 Months)
Mother's Maiden Last MILOT
Mother's First Name JESSICA
Phone 716-517-5342

Inpatient  Outpatient  Diagnostic  Amplification  Referral to EI

- Hearing Screening - Inpatient
- Hearing Screening - Outpatient
- Diagnostic Evaluation
- Amplification
- Referral to EI

Return to Child's Demographic Record
Screening, Diagnosis, and Early Intervention 2017

230,271 Newborns in NY

224,630 infants were screened

7,142 referred initial

217,877 passed initial

265 babies with permanent hearing loss enrolled in NYSEIP

9 babies with permanent hearing loss enrolled in a non-part C program

5,641 infants were not screened

964 received diagnostic audiology

18,535 passed follow-up

630 infants had hearing within normal limits

274 infants with permanent hearing loss enrolled in Early Intervention services

616 Infants died

53 Non-residents

731 NICU infants

462 Family declined

95 Infants transferred

230 Facility related

2,243 Homebirths

1,208 Other

Acronyms/Definitions

LTFU/LTD - Loss or Lost to Follow-Up / Loss or Lost to Documentation

NICU – Neonatal Intensive Care Unit

Non-residents – Families whose permanent residence is not NY

NYSEIP – New York State Early Intervention Program
The success of these programs depends on reporting, tracking and follow-up!

How the medical home can support reduced loss to follow-up:

- Get practice staff connected to NYEHDH-IS
- Determine an internal monitoring system for newborn hearing screening results and support/scheduling of follow-up as necessary
- Establish referral rapport with local audiological offices that offer specialized pediatric services
QUESTIONS
For access to training, training and technical assistance for NYEHDI-IS, please contact the NYS DOH EHDI program:

Phone: 518-473-7016
Email: nyedhi@health.ny.gov

NYEHDI TEAM

Michaelah Townley, MPH
NYEHDI Program Follow-Up Coordinator
Michaelah.Townley@health.ny.gov

Sharon Wu, M.S.
NYEHDI Program Data Coordinator
Sharon.Wu@health.ny.gov

Jessica M. Holst, M.S., CCC-SLP
NYEHDI Education and Training Contractor
holst.jessicam@gmail.com

Constance Donohue, AuD, CCC-A
Director, Bureau of Early Intervention
EHDI Vision

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.