American Academy of Pediatrics Tools for Medical Home Providers to Address Loss to Follow-Up / Documentation

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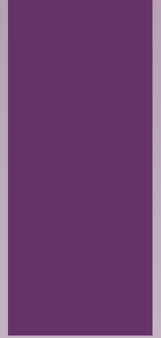

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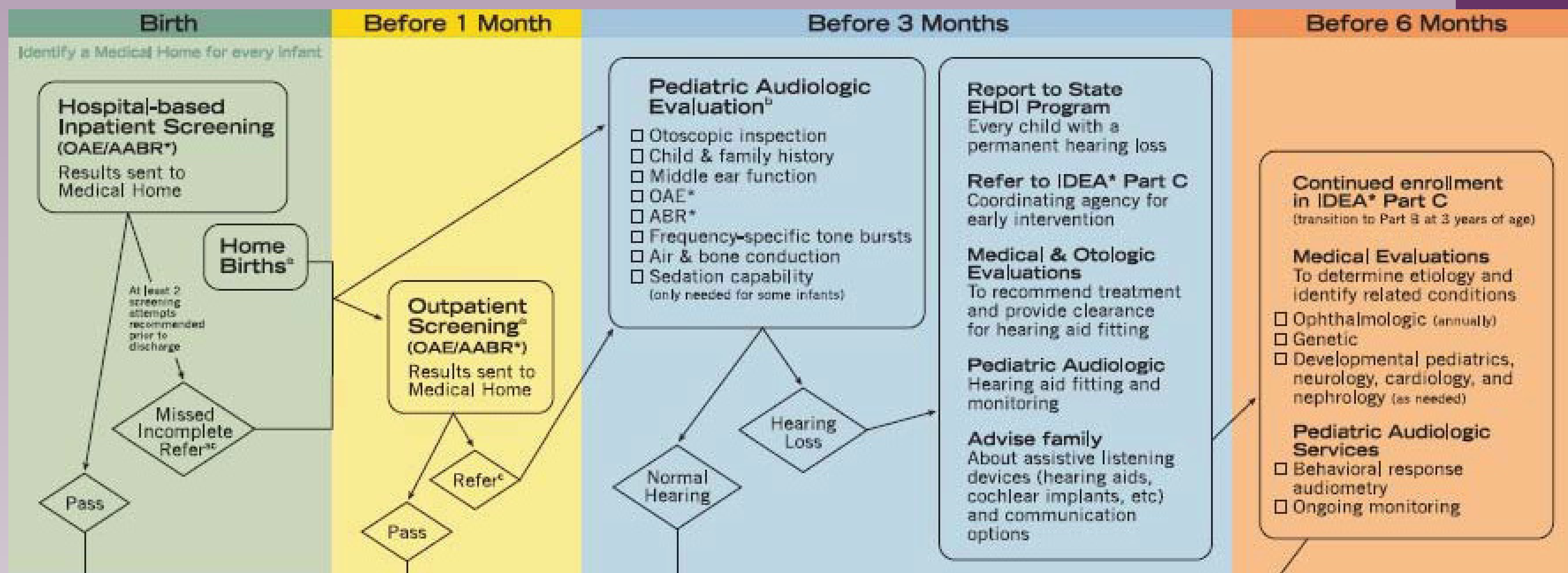
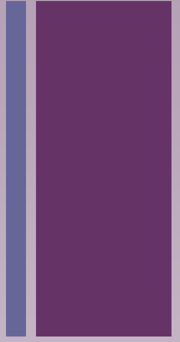


Ongoing Care of All Infants[e] From the Medical Home Provider

- **Provide parents with information about hearing, speech, and language milestones**
- **Identify and aggressively treat middle ear disease**
- **Provide vision screening and referral as needed**
- **Provide ongoing developmental surveillance and referral to appropriate resources**
- **Identify and refer for audiologic monitoring infants who have the following risk indicators for late-onset hearing loss:**
  - Parental or caregiver concern regarding hearing, speech, language, and/or developmental delay
  - Family history of permanent childhood hearing loss
  - Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or eustachian tube dysfunction
  - Postnatal infections associated with sensorineural hearing loss including bacterial meningitis
  - In utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis
  - Neonatal indicators—specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation
  - Syndromes associated with progressive hearing loss such as neurofibromatosis, osteopetrosis, and Usher syndrome
  - Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth disease
  - Head trauma
  - Recurrent or persistent otitis media with effusion for at least 3 months

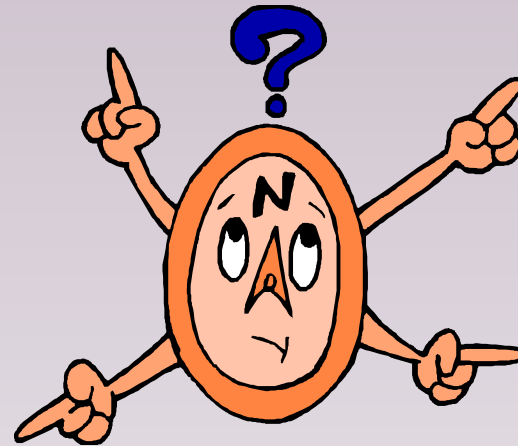
UNBHS



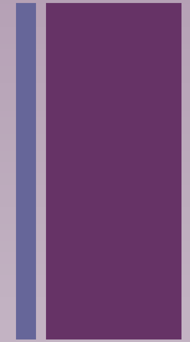
1:3:6

- Hearing (re)screening by 1 month
- Confirm results with a diagnostic test by 3 months (ABR)
- Appropriate intervention services (including amplification*, if desired) by 6 months

What are the biggest problems facing EHDI program!!



Lost to Follow-Up (3 Months)



39% - 2010

MMWR March 10, 2010, 59:8, M. Gaffney, J Eichwald et al

+ Lost to Treatment (Hearing Aids by 6 Months)

- In spite of 91% retest rate
- Only 39% fit with aids on time
- Late diagnosis
- Medicaid - more lost to follow-up
- NICU babies harder to treat because of compounding factors
- Distance from specialized centers

"Newborn Hearing Screening Follow-Up: Factors Affecting Hearing Aid Fitting by 6 Months of Age", Spivak et al. American J. Audiology, June 2009

+

Early Intervention

Only 60-70% of infants with hearing loss are enrolled by 6 months (CDC)

Barriers – M. Gaffney CDC

Hospital screening	• Technique and/or low numbers = high false positives • Presentation of results
Documentation	• Data reporting systems and ease • Importance
Audiology	• Lack of experienced “pediatric” audiologists • Communication
Family	• Cost and transportation • Language access • Mobility • Urgency

Challenges to medical home

Relatively low incidence of severe hearing loss	• One of the most common congenital disorder
Lack of physician knowledge and education*	• Different terminology • Misconceptions – success of UNHS*
Getting newborn results	• Difficulty with hospital • Integrating with electronic medical records
Retesting in office	• Reporting results*

Challenges to medical home

Family support

Working with EI

- Working with community agencies

Time constraints and financial constraints

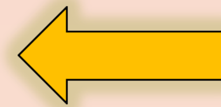
+ Before one month

Outpatient Rescreening

- Hospital
- Audiologist
- Retesting in Primary Care facility
- OAE
- ABR

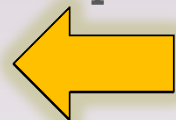
LTF/D

- Communication with family, hospital, audiologist
- Office protocol?
- Office staff can help
- Don't pass – DO TEST!!



+ Office Rescreening*

- How common?
  - 25% of pediatricians rescreen
  - NYS survey/Regional meetings
  - Many have OAEs in office
- Helpful to parents? Easier? Better?
- Who does it and are they trained?
  - Techs
- OAE? ABR? Both?
- Initial screen?
  - NY - 23%
- Need to report to State EHDI programs
  - Only 12% in NY



+ "Do not pass" - Parental support

- Explain and discuss results
  - Importance of hearing loss
- Use language that encourages follow-up
- Avoid negative and meaningless words
- Be sensitive to cultural meanings of words
- ALWAYS RETEST!!
- Assist in arranging retest and FOLLOW-UP

Before 3 months

- “Pediatric” audiological evaluation
- Report to state EHDI
- Early Intervention
- Family support, education and information
- Medical and ENT evaluation* – Genetics, Eye
- Hearing aids – if desired

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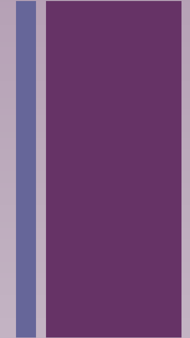
Most important predicator of success is meaningful and effective family involvement



Support reduces parental stress

Direct parent-to-parent support ranks as one of the strongest measures of family support – Hands & Voices

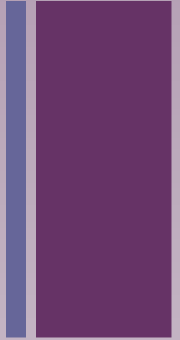
Less than 50% received support that they needed

Parents were more likely to get support when encouraged

Face-to-face interaction with professionals – major importance

Seaver, L. and Levine, J. (2010) Hearing Loss, Family Support and the Medical Home. ADVANCING Early Hearing Detection and Intervention in New York State. New York, NY

Before 6 months



Early Intervention services

Etiology and associated problems

- ENT
- Eye
- Genetics
- Neurology, Developmental Pediatrics and others if needed

Audiological follow-up

JCIH Risk Factors* - 40% of Hearing Loss Occurs after Newborn Period

- Family history of hearing loss
- NICU graduates
- Intrauterine infections like CMV
- Craniofacial, genetic and neurological conditions
- Serious head trauma – child abuse
- Meningitis
- Chemotherapy

Ongoing Care – "Bright Futures"

- Provide information about hearing, speech and developmental issues
- Aggressively treat middle ear disease (tympanometry)
- Routine hearing and vision screening (OAE, Sweep) – Referral to audiologist if not passed
- Developmental/autism screening – only 20% screen
- Referral if parental or PCP concern
- Refer if risk factor by 24 to 30 months - CMV
- Audiological evaluation of developmentally delayed or uncooperative children

AAP EHDI LTF/D Background Resources

GLOSSARY OF TERMS FOR NEWBORN HEARING SCREENING

The American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) Loss to Follow up/ Documentation (LTF/D) Workgroup has compiled a glossary of terms important to newborn hearing screening and resources related to LTF/D.

TERM	DEFINITION
Newborn hearing screening (NBHS)	Hearing screening performed shortly after birth, typically performed in hospitals prior to discharge involving the use of OAE or AABR.
Otoacoustic Emissions (OAE)	This test measures a response produced by the cochlea (outer hair cells) when a sound is presented to the ear. To conduct the test, a tiny probe is placed just inside the baby's ear canal and a soft click is presented, a tiny microphone measures the response produced by the baby's ear. The test is quick (about 5 to 10 minutes), painless, and may be done while the baby is sleeping or lying still. Thus, OAEs reflect the status of the peripheral auditory system extending to the cochlear outer hair cells.
Automated Auditory Brainstem Response (AABR)	This screening test measures how the hearing nerve responds to sound. Clicks are presented to the ear through a probe or soft earphones, and the neural response is measured through three electrodes placed on the baby's head. Automated ABR measurements reflect the status of the peripheral auditory system, the eighth nerve, and the brainstem auditory pathway.
Outpatient rescreening	An outpatient rescreening can take place at any of the following: 1. Hospital: Hospital screening protocols vary, and often include an outpatient screening stage. The specific technology used to conduct the outpatient screening should be based on the knowledge of how the inpatient screening was conducted. For example, when a baby fails an inpatient A-ABR screening, the outpatient screening must be conducted using A-ABR; if OAE is used auditory neuropathy will be missed. Some hospitals will do the rescreen before the baby leaves the hospital. 2. Provider Office: Ideally the initial newborn hearing screening and rescreening (if necessary) will take place at the birthing hospital. However, in some cases once the baby is discharged from the hospital, a provider may conduct a rescreen in the office as needed. 3. Audiologist: Similar to the provider office, a rescreen may also take place at the audiologist office.
Lost to follow up	For infant who did not pass newborn hearing screening, "lost to follow-up" refers to a failure to receive the next step of treatment, be it rescreen or comprehensive audiological evaluation.
Lost to documentation	Failure to report the results from hearing screening, rescreening, diagnostic services, and/or treatment services which are needed for comprehensive surveillance and monitoring by EHDI and the medical
Lost to treatment	Failure for a child with an identified hearing loss to receive needed therapeutic services and failure for families to receive needed information to support decisions regarding treatment options.
Medical home	A model for providing high quality primary care that addresses and integrates health promotion, acute care and chronic condition management in a planned, coordinated, and family-centered manner.
Late onset hearing loss	A hearing loss that is not present at birth and the newborn hearing screening would result in 'pass'.
Auditory Neuropathy	Children with auditory neuropathy have evidence of normal cochlear function, but show impairment in the function of the auditory nerve. Functional hearing can often be quite impaired and diagnosis and treatment can be confusing and complicated.

Early Hearing Detection & Intervention Program

NEWBORN HEARING SCREENING: LOST TO DOCUMENTED FOLLOW UP CONSIDERATIONS FOR THE MEDICAL HOME

Since 2000, the percentage of newborns screened for hearing loss dramatically increased from 52 to 95 percent. However, almost half of the children who 'do not pass'* hearing screening tests lack a documented diagnosis. The infant's primary care medical home provider plays an important role in ensuring that timely follow up and the appropriate documentation of that follow up occur. Without the active asssitance of the medical home the infant may be considered "lost" in the early hearing detection and intervention (EHDI) system, which undermines the potenital benefits of newborn hearing screening. A 'wait and see' approach is never appropriate.

An infant who does not pass his/her newborn hearing screen has a potential **developmental emergency**!

**Do not pass includes babies that have 'failed' or missed the hearing screening or for those who had an invalid, un-interpretable result.*

WHAT CAN A NEWBORN IDENTIFIED WITH POSSIBLE HEARING LOSS BE "LOST" TO?

Lost to follow up: For infants who did not pass newborn hearing screening, "lost to follow-up" refers to a failure to receive the next step of treatment, be it rescreen or comprehensive audiological evaluation.

Lost to documentation: Failure to report the results from hearing screening, rescreening, diagnostic services, and/or treatment services to the state EHDI program and the medical home. This data is needed for comprehensive surveillance and monitoring to ensure infants receive recommended services. Lost to documentation can mean:

- Hospital does not record and/or report results of first screen
- Hospital does not record and/or report results of second screen
- Audiologist does not report results
- Medical home provider does not record and or report the results of the rescreen

Lost to treatment: Failure for a child with an identified hearing loss to receive needed therapeutic services and failure for families to receive needed information to support decisions regarding treatment options

WHAT IS THE MEDICAL HOME'S ROLE IN REDUCING THE PERCENTAGE OF INFANTS THAT DO NOT PASS THE NEWBORN HEARING SCREEN AND WHO ARE THEN CONSIDERED LOST TO DOCUMENTED FOLLOW UP?

The following information outlines specific actions the medical home can take to reduce the percentage of infants who do not pass a newborn hearing screen who either do not receive follow up care or whom follow up is not reported back to the state EHDI programs. *It is important to note that the actions outlined below are specific to reducing lost to documented follow up. There are many more recommendations for providers for the overall EHDI process that are not listed here. For additional information, please see the 2007 Joint Committee on Infant Hearing Position Statement and EHDI Guidelines for Pediatric Medical Home Providers.*

PRACTICE CONSIDERATIONS

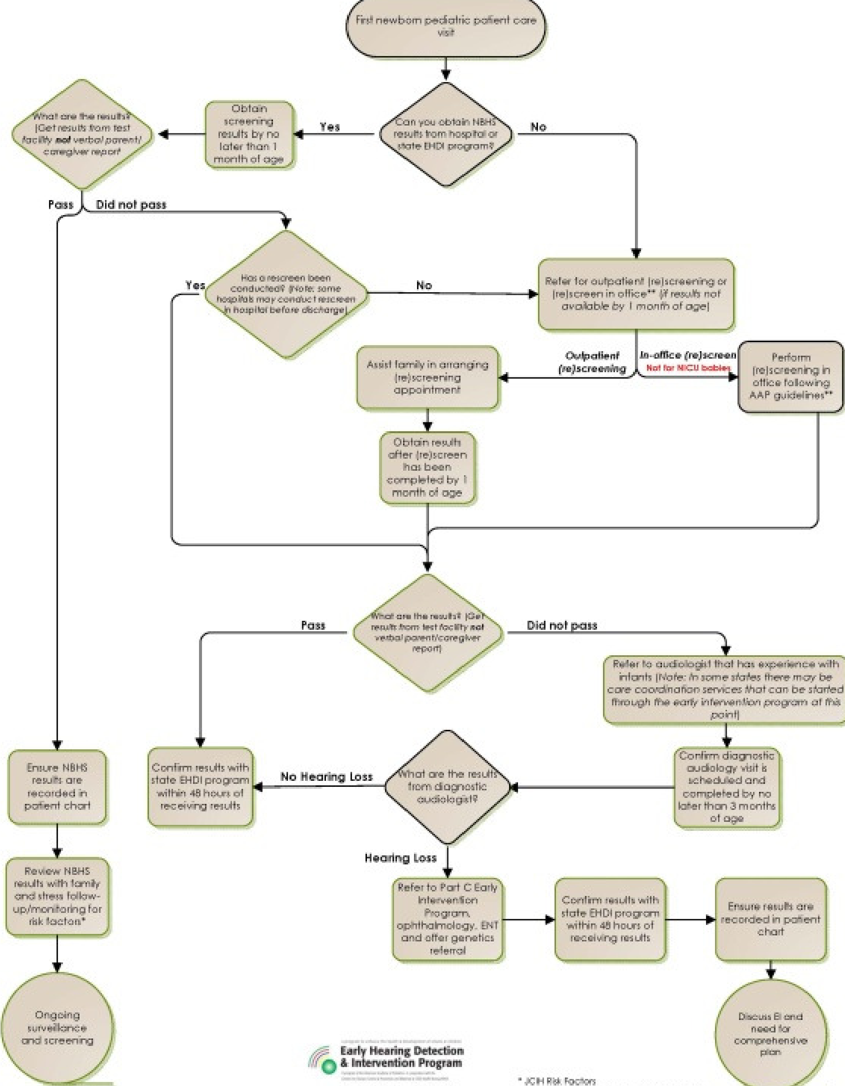
Medical homes should obtain, document, and discuss all screening test results and risk factors** which includes:

- Confirm that initial newborn hearing screening results have been obtained for all infants as soon as results are available but no later than 1 month. If results are not received, obtain results from

Early Hearing Detection & Intervention Program

**JCIH Risk Factors

AAP EHDI LTF/D Guidelines & Checklist



1-3-6 NEWBORN HEARING SCREENING CHECKLIST

Patient Name: **Patient DOB:** **Date of Visit:**

1 INITIAL SCREENING *(by no later than 1 month of age)*

Question	Yes	No ⇨	Action
Has the child had a newborn hearing screening?	Yes	No ⇨	Schedule initial screen
Did you obtain the test results from the screening hospital or state EHDI program?	Yes	No ⇨	Contact the hospital or state EHDI program
Are the results recording in the patient's chart?	Yes	No ⇨	Record test results in patient chart
Did the child pass the newborn hearing screening?	Yes	No ⇨	Schedule rescreen appointment
Have the results been reported to the state EHDI program?	Yes	No ⇨	Confirm results have been reported to state EHDI program within 48 hours of receiving them.
Have results been discussed with family?	Yes	No ⇨	❑ For a child that passed, stress the importance of ongoing surveillance and risk factors* ❑ For a child that did not pass, discuss the need for follow-up and assist in arranging a rescreening
Has a rescreening occurred (if the initial screen resulted in 'did not pass' or if otherwise necessary)?	Yes	No ⇨	Schedule rescreen appointment

RESCREENING *(by no later than 1 month of age)*

Where will the rescreening be performed?

- ✓ If hospital/outpatient center, when is the rescreening appointment?
- ✓ If conducted in office:
  - Determine what screening equipment was used at the hospital.
  - Follow the AAP office rescreening guidelines.

❑ Hospital:

❑ Office
❑ Other (specify):

Location:

Date:

Question	Yes	No ⇨	Action
Did the child pass the rescreening?	Yes	No ⇨	Send child to audiologist with pediatric expertise for diagnostic evaluation.
Are the results recorded in the patient chart?	Yes	No ⇨	Record results in patient chart.
Have the results been discussed with the family?	Yes	No ⇨	❑ For a child that passed, stress the importance of ongoing surveillance and risk factors* ❑ For a child that did not pass, discuss the need for follow-up and assist in arranging an audiological evaluation
Have the results been reported?	Yes	No ⇨	Confirm results have been reported to state EHDI program within 48 hours of receipt

3 DIAGNOSTIC EVALUATION *(by no later than 3 months of age)*

Question	Yes	No ⇨	Action
If the child did not pass the rescreening, was he/she referred to an audiologist with expertise in pediatrics?	Yes Provider: Date of Visit:	No ⇨	Refer to audiologist with expertise in pediatrics
Were the results of the diagnostic test normal?	Yes	No ⇨	Discuss EI and need for comprehensive plan
Have the results been discussed with the family?	Yes	No ⇨	❑ For a child that passed, stress the importance of ongoing surveillance and risk factors* ❑ For a child that did not pass, discuss EI and need for comprehensive plan
Have the results been reported?	Yes	No ⇨	Confirm results have been reported back to state EHDI program within 48 hours of receipt

6 EARLY INTERVENTION *(by no later than 6 months of age)*

Question	Yes	No ⇨	Action
If the child was diagnosed with a hearing loss, was he/she referred for early intervention and multi-disciplinary evaluation?	Yes Date of visit:	No ⇨	Provide early intervention referral and ophthalmology, and ENT, offer genetics

ONGOING SURVEILLANCE AND SCREENING

Continue to perform ongoing surveillance and screening for late-onset hearing loss –particularly those children with risk factors.

Early Hearing Detection & Intervention Program

*JCIH Risk Factors

Medical Home and LTF/D AAP EHDI Task Force

Obtain, document, and discuss all screening test results and risk factors by one month

- Whenever possible information should be received from the hospital rather than the parent
- Work with local birthing facilities to establish best method for obtaining test results

Coordinate care of a child that has a 'do not pass' screening result or for whom you cannot obtain the documented screening results

- Either screen, rescreen or arrange screen or rescreen by one month
- Medical Home takes lead in scheduling - Assist parents with rescreen appointment

Medical Home and LTF/D AAP EHDI Task Force

Confirm results with state EHDI program within 48 hours

- Need to learn state reporting program

IF 'do not pass' the second screen, refer to audiologist that has experience with infants and ensure follow-up appointment is scheduled

- Confirm appointments and notify state EHDI program
- refer to CDC EHDI Directory – EHDI PALS

Ensure family is referred to local EI program

- Medical home should get parent/family to release medical information/records to PCP so they can obtain the results

Medical Home and LTF/D AAP EHDI Task Force

Dedicated staff person in the practice

- Obtain all screening results
- Coordinate the education/support of families
- Relationship with State EHDI program

Provide education and support to families

- Hearing, speech, and language milestones
- Discuss and explain all test results, next steps, and importance of follow-up
- Confirm with family that follow-up appointments have been made and kept
- Help to arrange transportation and social service support

Culturally competent and health literate appropriate information

- Hands and Voices, Guide-By-Your-Side, NCHAM, etc.
- Educational options

AAP EHDI LTF/D Rescreening Guidelines

AAP HEARING SCREENING GUIDELINES FOR MEDICAL HOMES

GUIDELINES AT A GLANCE:

- ✓ Except in rare circumstances, Medical homes should NOT conduct the initial newborn hearing screening
- ✓ Proper equipment (e.g. AABR) is required for screening in order NOT to miss auditory neuropathy. For this reason, it is very important that the medical home know what screening equipment is used at their local birthing facilities.
- ✓ If you are conducting a hearing screening, you are obligated to report the results to the state EHDI program

If the medical home will be performing a hearing re-screening, the following are crucial to a successful screening:

REPORTING

- Re-screening in the medical office comes with an important **obligation to report all** normal and abnormal **screening results** to the state EHDI system (and in some states it is required by law).
- To find your EHDI state coordinators: http://www.infanthearing.org/status/cnhs.html.

EQUIPMENT

- Re-screening of infants must be performed by a **physiologic measurement**, not by assessing behavioral responses to environmental sounds or noises. Currently, the technology that is most commonly available and affordable for such office-based re-screening is "otoacoustic emission" or "OAE" technology.
- The equipment used for re-screening must be **calibrated by the manufacturer**, with a declaration that the device is capable of separating "pass" from "not-pass" at a level that can detect a hearing loss of at least 30 dB.
- The equipment must be **maintained and recalibrated on a regular basis (at least annually)** or more frequently if recommended by the manufacturer.
- Babies with auditory neuropathy will pass an OAE (normal middle and inner ear function) but not pass an AABR (nerve deficits). If an infant does not pass an automated ABR screening (AABR) in the hospital and then passes an OAE, it DOES NOT assure normal hearing. This child must be rescreened with an AABR. If however, the infant does not pass the OAE than a hearing loss is likely and the infant must be referred immediately for further evaluation
- Infants who were hospitalized in the newborn intensive care unit (NICU) are at much higher risk for hearing loss, particularly auditory neuropathy which can only be determined with an AABR or ABR. These babies should only be screened with an AABR and if they do not pass, they should be referred to an audiologist with experience with infants to perform a rescreen with an AABR.

PROPER SCREENING TECHNIQUE

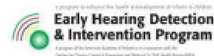
- It is best to have a **quiet environment** for office-based testing to minimize the risk of ambient noise interfering with the screening results.
- Office personnel who perform the re-screening should be **trained and experienced** in screening infants and children.
- It is important that the infant is only rescreened at a single visit in the office so that there is no delay in identification of infants with hearing loss. They should be referred to a qualified infant audiologist.
- During the rescreening visit, there should be no more three tests of each ear with the OAE probe. If after three probe tests, the ear or ears do not pass the baby should be referred to a qualified infant audiologist.
- At the time of re-screening, **both ears should always be tested**, even if only one ear did not pass the hospital-based hearing screening test.

COMMUNICATION OF RESULTS TO FAMILY

- Screening results should be conveyed to families in a culturally competent, sensitive manner to ensure understanding.
- The results of hearing screening should be explained to families in a way that conveys the screen is not a definitive diagnosis so as not to cause undue anxiety, but **strongly** encourages the family to take the next appropriate step in adhering with a diagnostic testing.

DELAYED-ONSET HEARING LOSS

- A passing screen at birth does not assure that delayed-onset hearing loss will not later be diagnosed
- Referral for pediatric audiology evaluation should be made when there is caregiver concern about hearing, a delay in the child's language development, or when there are identified JCIH risk factors for childhood hearing loss.



Guidelines at a glance:

✓Except in rare circumstances, medical homes should NOT conduct the initial newborn hearing screening.

✓Proper equipment (eg, automated auditory brainstem response [AABR]) is required for screening in order NOT to miss auditory neuropathy. For this reason, it is very important that the medical home know what screening equipment is used at local birth facilities.

✓If you are conducting a hearing screening, you are obligated to report the results to the state EHDI program.

NICU graduates

How to Reach PCPs?

Decide who you want to reach? Who is reachable?

Face to face visits
- Physician champion - enthusiastic
- Office managers – make appointment
- Brief and focused
- Bring gifts ☺

Web site with online/printable materials
- Handouts – patient education
- "Just-in-time" – desktop
- Journals?

Mobile applications
- Younger
- Must be easy to use

Less Effective
- Conference/phone calls
- Grand rounds ?
- Clinical guidelines

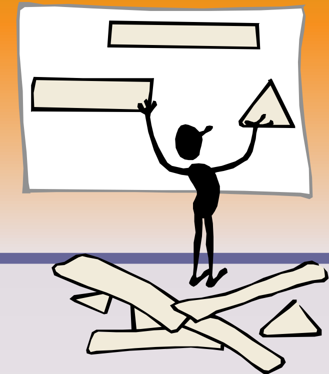
Stevenson and Biernath 2010, Lieser and Levine 2012, Texas EHDI Pilot Program 2011

Can the Medical Home Reduce LTF/D?

It's tough to make predictions,

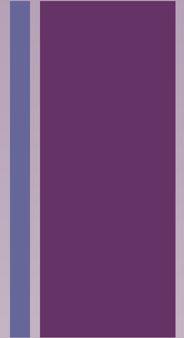
especially about the future.

Yogi Berra



Link to Resources

(Webinars, Videos, Algorithms, etc)



http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx

http://www.youtube.com/watch?v=FexE1ll5oQ4&feature=youtu.be

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Questions?