**NCHAM Webinar Series** 

## Meeting the Needs of Physicians in Support of EHDI

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### To Achieve EHDI's 1-3-6 Goals...

- Hearing (re)screening by 1 month
- Diagnostic test by **3 months**
- Intervention (including amplification, if desired) by 6 months

## ....a Team approach is needed.

#### The role of the Medical Home: Coordination, Communication, Access to EHDI



Screening confirmation

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|---|--|--|---|-------|
| 42 (0.3304 X0944  |  | Facility Logar   | Regional 💌 💽                                      |       |
|   | Summary Info for   | Teres, Rosemary  |   |       |
| Name: Teres, Rosenary<br>Medical ID:<br>Birth Date: 1/6/2022<br>Gender: F   | Most Conclusion Result<br>Inpatient He Pass<br>Inpatient Lef Pass<br>Inpatient Ri Pass | Mare<br>TEOAE 11/12/2003<br>TEOAE 11/12/2003<br>TEOAE 11/12/2003 | Diagnostic Tests<br>No Information Available      | Mare  |
| Correct State Passed Screening<br>Newsey: Well Bahy<br>Resp Facility: Logan Regional<br>Binth Facility: Resp Regional<br>Pethoary Care<br>Pavides:<br>Primary<br>Contact: Lunis, Nathan | Resonnended Action <u>Mice</u><br>His Information Available                            |  | Audiogram <u>More</u><br>No Information Available |       |
| State History More<br>lived Inpatient Passed Screen 11/12/2003 12.1<br>faced Screen Need Inpatient 11/12/2003 12.4  | Hearing Status<br>No Information A   | Mass   | Risk Indicators<br>No Information Available       | Mara  |
| Red Ingatient Passed Screeni 3/20/2003/9:52   | Letter Hatory<br>No Information A  | Mare   | Amplification<br>No information Appliable         | Mare. |
| Status Balancy Mass<br>1/12/2003 12.1 In Progress Complete  | NO ENDINADOR A   |  | THE EXCITATION PROPERTY                           |       |
|   | Retes  | More   |   |       |

Reporting



Diagnostics



El Services & Family Support



Specialists



Early childhood screening

## Purpose of 2012 Physician Survey

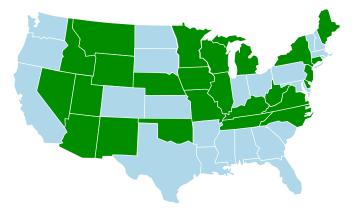
- ✓ Understand the degree to which medical homes are engaged in EHDI systems.
- ✓ Update our understanding of physician attitudes & knowledge re: EHDI, assessing progress since 2005.
- ✓ Drive strategies to support physicians in their role in EHDI.





## Methods

- ✓ Invitation to participate sent to state EHDI coordinators
- ✓ 26 states participated (n=2,172 responses; 11.5% response rate)



- Physicians who care for children identified by EHDI coordinators, typically w/support from state AAP, AAFP chapters
- ✓ All received hard copy in the mail along with URL to answer survey online
- Cost sharing between NCHAM (materials, analysis) and State (postage, labor)



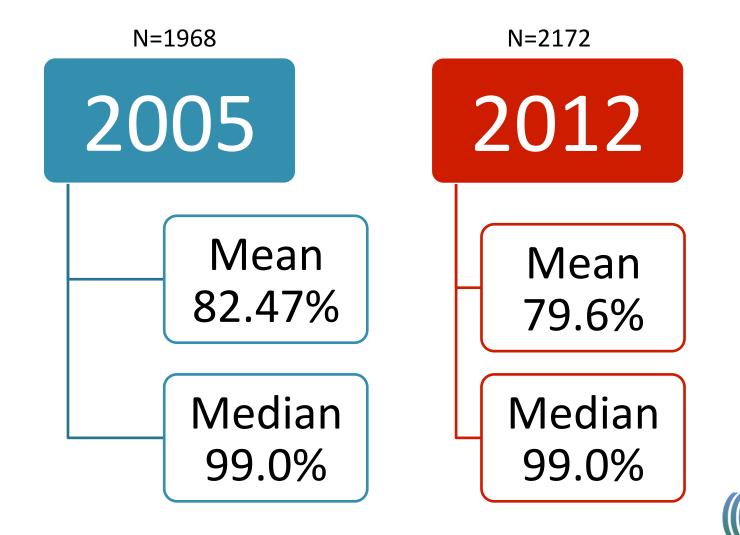
#### **Demographics of Respondents**

2005

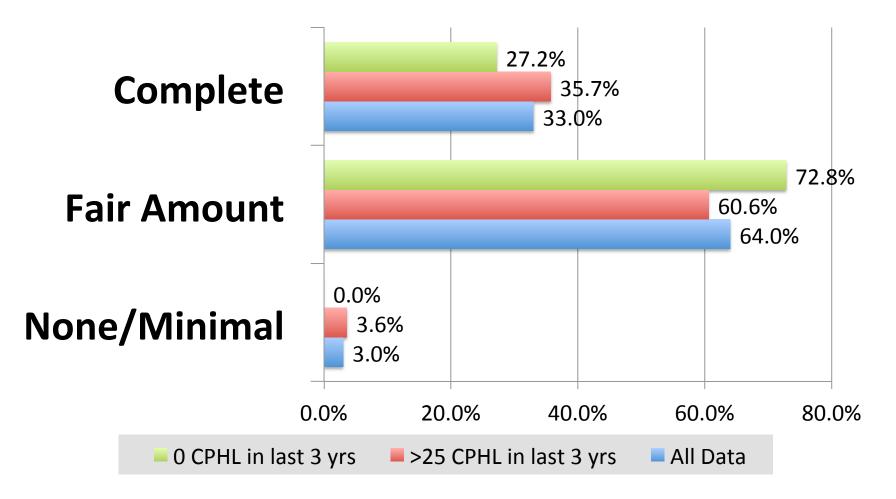
2012

|   | 2005         | 2012         |   |
|---|--------------|--------------|---|
| Type of Provider                        |              |              |   |
| Pediatrician                            | 60.3%        | <b>53.8%</b> | [ |
| Family Practice Physician               | 27.8%        | <b>27.4%</b> |   |
| Otolaryngologist                        | 3.0%         | 7.2%         |   |
| Neonatologist                           | 2.8%         | <b>3.1%</b>  |   |
| OB/GYN                                  | 0.5%         | 0.6%         | _ |
| Practice Location                       |              |              |   |
| Metro area                              | <b>62.5%</b> | <b>56.5%</b> |   |
| Small Town                              | <b>24.1%</b> | <b>25.5%</b> |   |
| Rural Area                              | 13.3%        | <b>18.0%</b> | _ |
| Type of Practice                        |              |              |   |
| Private Practice or<br>Community Clinic | 78.2%        | 81.8%        |   |
| Hospital                                | 10.8%        | 10.0%        |   |
| Medical School or<br>University         | 6.1%         | 3.8%         |   |
| Other                                   | 4.0%         | 4.9%         |   |
| Gender                                  |              |              | 2 |
| Male                                    | 53.2%        | 51.8%        |   |

National Assessment and Management Utah State University™ For newborns in your practice during the past year, estimate the percentage for which you received initial newborn hearing screening results?

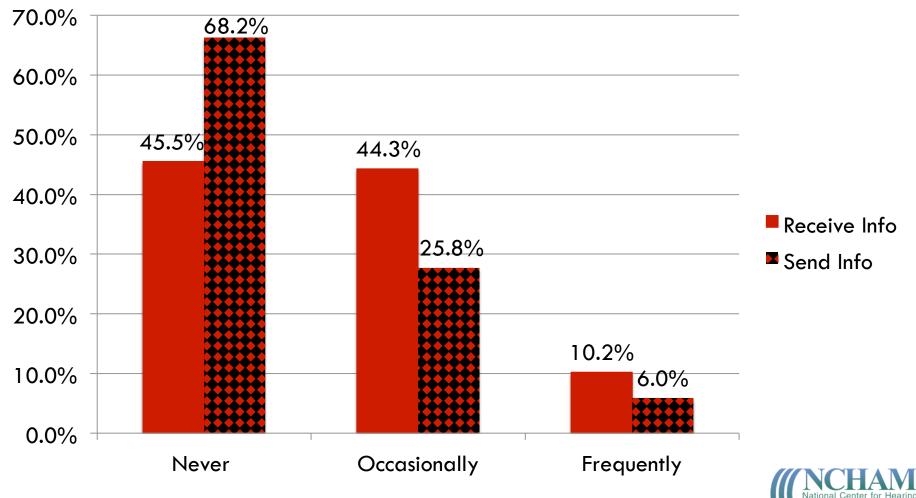


## How Much Trust Do You Have in Newborn Hearing Screening Results?





# How often do you connect with your state EHDI program?



#### What is your best estimate of the earliest age at which:

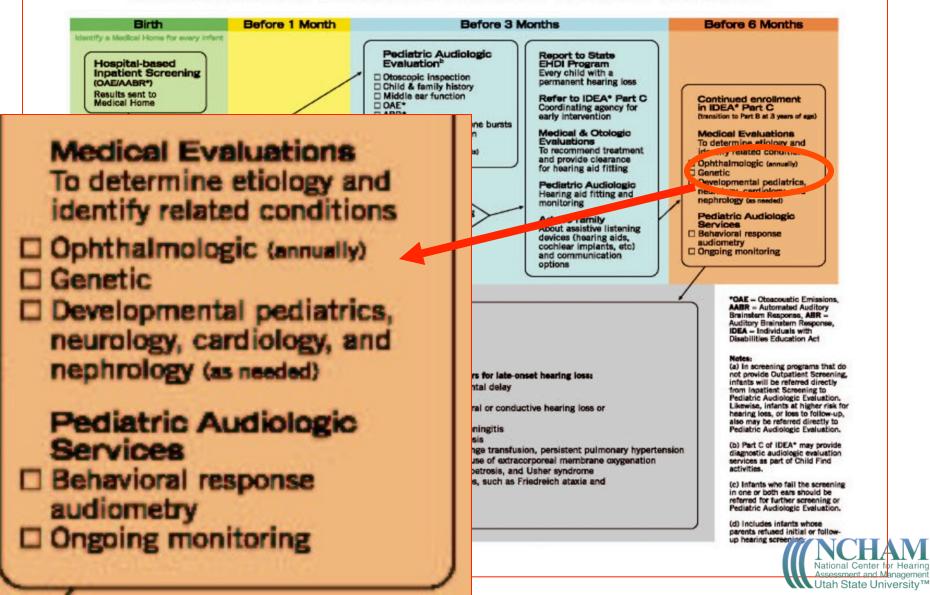
| <1 mo          | 1-3 mos        | 4-6 mos      | 7-9 mos      | 10-12 mo     | >12 mo       |   |
|----------------|----------------|--------------|--------------|--------------|--------------|---|
| 75.7%<br>41.0% | 11.7%<br>51.9% | 7.1%<br>6.1% | 4.2%<br>0.3% | 0.1%<br>0.7% | 1.2%<br>0.8% | <ul> <li>a. A newborn not passing the<br/>hearing screening should receive<br/>additional testing</li> </ul>      |
| 51.9%<br>20.9% | 10.8%<br>37.0% |              | 9 20/        | 10.2%        | 9.3%<br>5.3% | <ul> <li>b. A child can be definitively</li> <li>diagnosed as having a</li> <li>permanent hearing loss</li> </ul> |
| 38.3%          | 9.0%           | 11.2         | 47.3         | %            | 18.1%        | c. A child can begin wearing  |
| 12.2%          | 26.9%          | 31.9%        | 3.7%         | 16.6%        | 9.1%         | hearing aids  |
| 61.6%<br>26.9% | 8.0%<br>33.3%  | 39           | .1%          | 0.4%<br>8.1% | 7.0%<br>4.2% | d. A child with permanent hearing<br>loss should be referred to early<br>intervention services                    |

2005/2012 Comparison



#### **American Academy of Pediatrics**

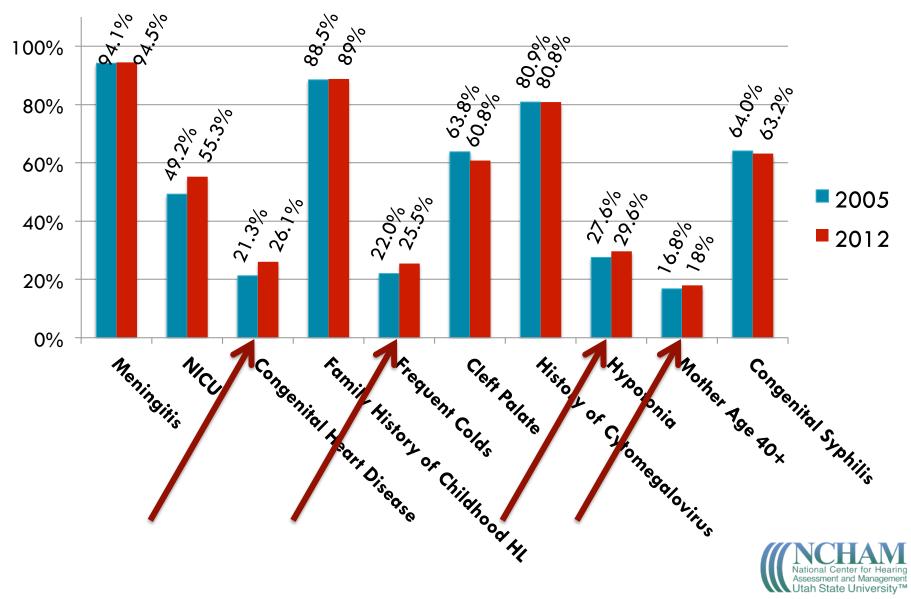
#### Universal Newborn Hearing Screening, Diagnosis, and Intervention Guidelines for Pediatric Medical Home Providers



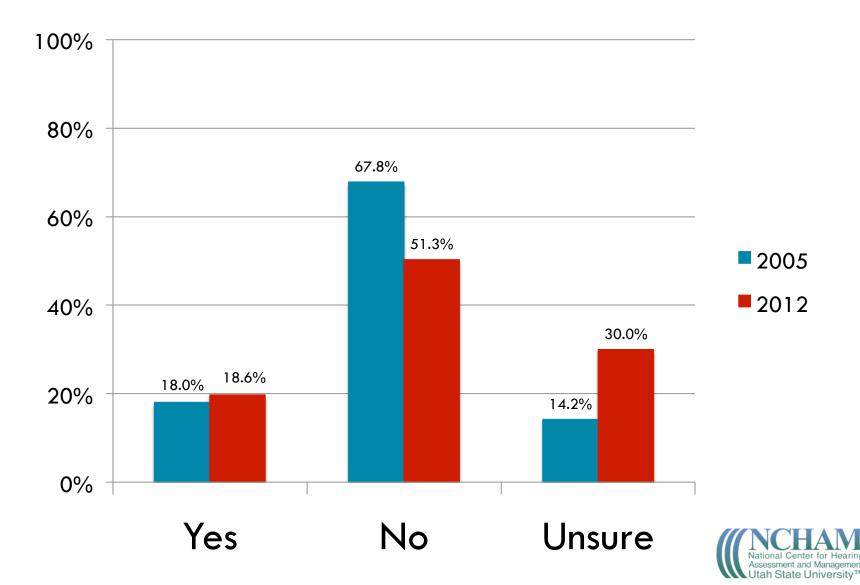
List any specialists to whom you would routinely refer the family of a child with confirmed permanent hearing loss (open-ended question)

| Specialist                     | 2005  | 2012  |
|--------------------------------|-------|-------|
| ENT/Otolaryngology*            | 75.6% | 73.4% |
| Geneticist*                    | 8.8%  | 9.3%  |
| Ophthalmologist*               | 0.9%  | 2.2%  |
| Audiologist                    | 41.2% | 53.0% |
| Speech Language<br>Pathologist | 22.9% | 27.0% |
| Early Intervention             | 11.4% | 12.0% |
| Neurologist                    | 7.0%  | 5.6%  |

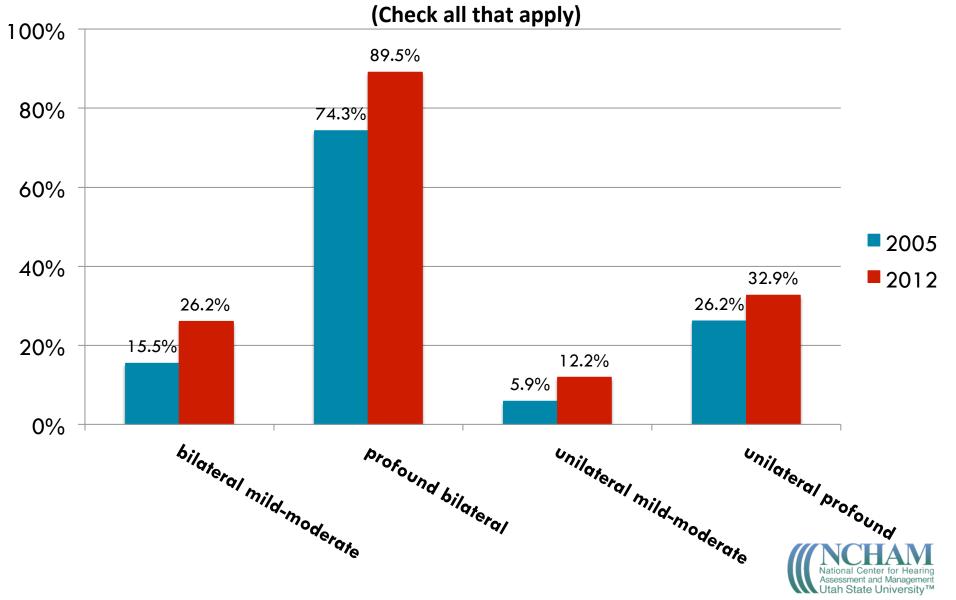
## Which of the following conditions puts a child at risk for permanent late onset hearing loss? (Check all that apply)



## Did your training prepare you adequately to meet the needs of infants with permanent hearing loss?



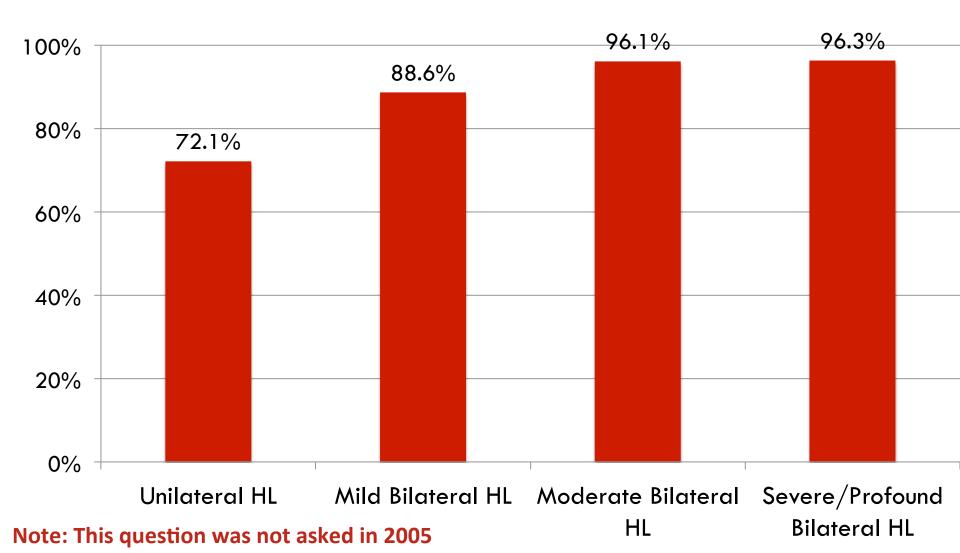
# Children with which of the following hearing losses may be candidates for cochlear implants?



#### How confident are you in talking to parents of a child with permanent hearing loss about...?

|                   | 200                   | 12       |                  |   |                   | 20.      | 12     |                  |
|-------------------|-----------------------|----------|------------------|---|-------------------|----------|--------|------------------|
| Very<br>Confident | Somewhat<br>Confident | Unsure   | Not<br>Confident |   | Very<br>Confident | Somewhat | Unsure | Not<br>Confident |
| Not               | included in           | 2005 su  | vey              | NBHS Process  | 54.0%             | 37.2%    | 0.0%   | 8.8%             |
| 14.5%             | 64.2%                 | 0.4%     | 20.9%            | Causes of HL  | 28.5%             | 56.9%    | 0.0%   | 12.7%            |
| 7.2%              | 35.0%                 | 1.1%     | 56.7%            | Communication<br>Options (e.g., ASL,<br>LSL, Cued Speech) | 12.8%             | 37.8%    | 0.0%   | 49.3%            |
| 14.4%             | 58.6%                 | 0.9%     | 26.1%            | Unilateral or<br>Mild Hearing<br>Loss<br>Consequences     | 28.0%             | 54.7%    | 0.0%   | 17.3%            |
| 16.5%             | <b>49.7%</b>          | 0.9%     | 32.9%            | Bilateral<br>moderate to<br>profound HL<br>Consequences   | 21.7%             | 48.3%    | 0.0%   | 30.0%            |
| 6.3%              | 28.0%                 | 2.9%     | 62.7%            | Cochlear<br>implant<br>candidacy                          | 9.8%              | 33.9%    | 0.0%   | 56.3%            |
| Not               | included in           | 2005 sur | vey              | What to do next<br>when a child<br>diagnosed              | 37.0%             | 49.7%    | 0.0%   | 13.3%            |

# Which of the following can have an impact on speech and language development? (Check all that apply):



## Do you do hearing screening for infants and young children in your office?

## Yes -28.6%

## No -71.4%



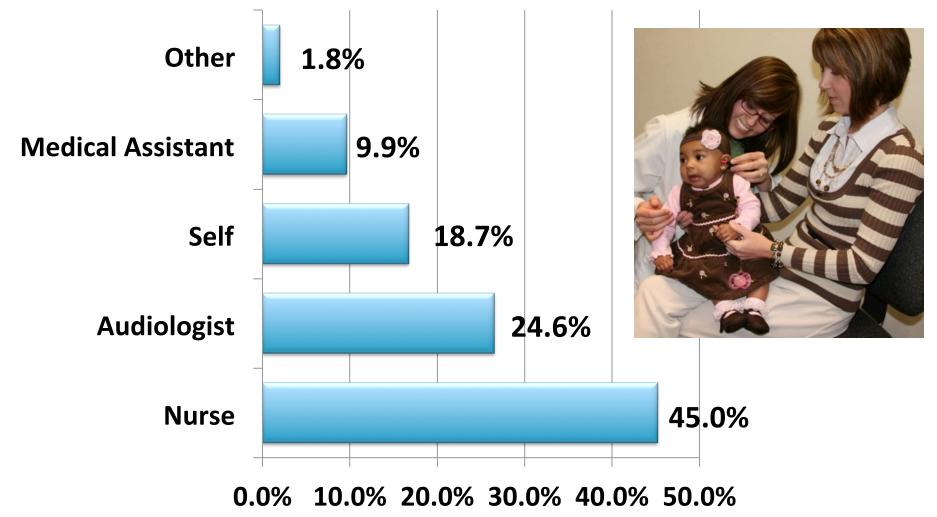


| If yes, who are you scr   | eening?   |
|---|---|
| Newborns who <u>do not</u> pass NBHS in<br>hospital                                 | 50.2%   |
| Newborns for whom you <u>cannot</u><br><u>obtain</u> NBHS results                   | 43.3%   |
| All newborns regardless of previous tests   | 15.4%   |
| Children <u>ages 1-3 years</u> as part of their annual check-ups                    | 50.9%   |
| Children of <u>parents who voice</u><br><u>concerns</u> about their child's hearing | 81.4%   |
| Note: This question was not asked in 2005   | National Center for Hearing<br>Assessment and Management<br>Utah State University <sup>TM</sup> |

# How often do you use each of the following to screen hearing in your office?

|   | Never | Occasionally | Frequently | Always |
|---|-------|--------------|------------|--------|
| a. AABR                                       | 71.6% | 14.4%        | 10.3%      | 3.7%   |
| b. Response to<br>sounds/<br>noisemakers      | 17.1% | 25.3%        | 36.4%      | 21.2%  |
| c. Caregiver<br>interview or<br>questionnaire | 9.7%  | 12.5%        | 35.4%      | 42.4%  |
| d. OAE  | 34.2% | 13.4%        | 29.2%      | 23.2%  |
| e. Tuning Fork                                | 53.5% | 33.7%        | 9.7%       | 3.1%   |
| f. Tympanometry                               | 21.1% | 28.2%        | 32.5%      | 18.3%  |

# Who does most of the hearing screening in your office? (Choose one)





#### Number of children seen with permanent hearing Loss in your practice during last 3 years

|  | <b>0</b><br>(n=672) | <b>1-3</b><br>(n=858) | <b>4-9</b><br>(n=310) | <b>10-24</b><br>(n=141) | <b>25-49</b><br>(n=29) | <b>50+</b><br>(n=30) |
|--|---------------------|-----------------------|-----------------------|-------------------------|------------------------|----------------------|
| Routinely refer the family<br>of a child with permanent<br>hearing loss to a geneticist.                 | 4.8%                | 7.9%                  | 16.1%                 | 17.7%                   | 13.8%                  | 50.0%                |
| Believe hearing aids can be<br>fit for children 0 to 3<br>months of age.                                 | 34.4%               | 38.9%                 | 42.3%                 | 39.6%                   | 46.4%                  | 66.7%                |
| Believe infants with<br>bilateral mild-moderate<br>hearing loss are candidates<br>for cochlear implants. | 25.6%               | 28.6%                 | 30.3%                 | 18.4%                   | 17.2%                  | 13.3%                |
| Believe unilateral hearing<br>loss affects speech and<br>language development                            | 71.0%               | 73.2%                 | 75.5%                 | 75.2%                   | 75.9%                  | 90.0%                |

What correlates with knowledge about hearing loss and treatment?



- Number of children seen w/hearing loss? (substantial effect)
- Perceived adequacy of training? (some effect)
- Years of experience in pediatrics? (little effect)
- Percent of practice comprised of 0-5 year olds? (small positive effect)



### Survey Take-Home Messages

- Physicians are getting NBHS results, but little other communication w/state EHDI program
- Some skepticism re: trust in NBHS results
- No better knowledge re: 1-3-6 rule
- No better knowledge re: risk factors
- Feel less prepared in terms of training
- Apx. ¼ perform hearing screening, often via noisemakers and parent interview

#### There's a lot more work to do!

### How can this information be used by EHDI?

Reported coordinator activities:

#### **Raise awareness**



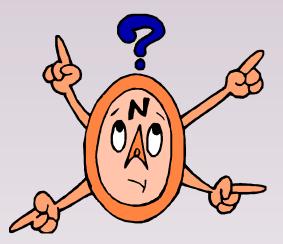
- ✓ Share results w/state EHDI Advisory Board
- ✓ Present at grand rounds
- ✓ Present at physician conferences, audiology task forces

#### **Educate & provide resources for physicians**

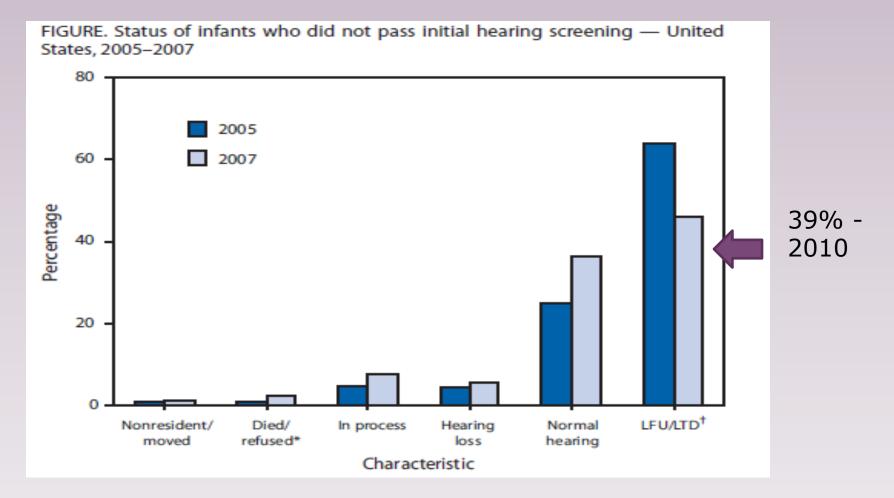
- ✓ Engage Chapter Champions in training
- ✓ Target high LTF hospitals, support medical homes in area
- ✓ Conduct follow up surveys to "drill down"
- Guide EHDI policies and practices
  - ✓ Target physician behaviors in QI efforts
  - ✓ Interdisciplinary training

## What are the biggest problems facing EHDI programs?





## Lost to Follow-Up (3 Months)



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. <u>American J. Audiology</u>, June 2009

## **Early Intervention**

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



### Barriers – M. Gaffney CDC

| Hospital<br>screening | <ul> <li>Technique and/or low numbers = high false positives</li> <li>Presentation of results</li> </ul> |
|-----------------------|--|
| Documentation         | <ul> <li>Data reporting systems and ease</li> <li>Importance</li> </ul>                                  |
| Audiology             | <ul> <li>Lack of experienced "pediatric"<br/>audiologists</li> <li>Communication</li> </ul>              |
| Family                | <ul> <li>Cost and transportation</li> <li>Language access</li> <li>Mobility</li> <li>Urgency</li> </ul>  |

## Challenges to medical home

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



At least 90% of children who are either born deaf or lose their hearing are born to hearing parents



Conversely, 90% of the children of deaf parents are hearing

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

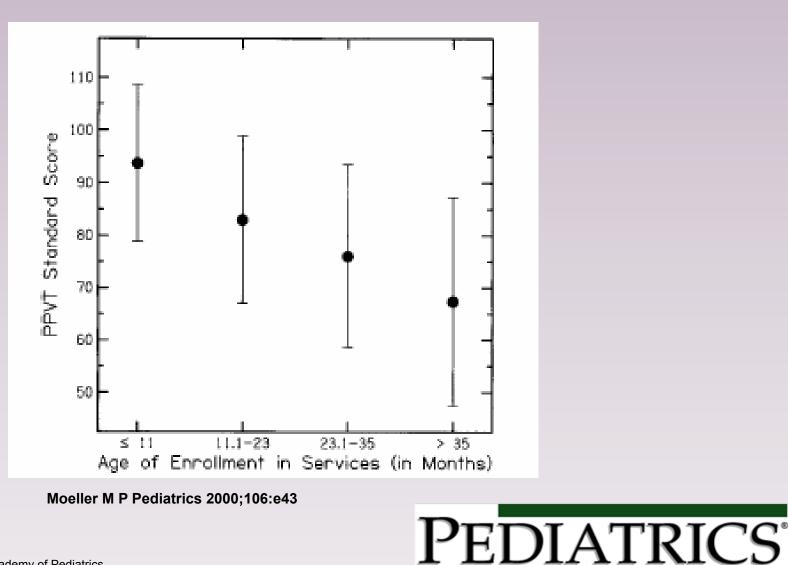
Less than 50% received support that they needed

Parents were more likely to get support when encouraged

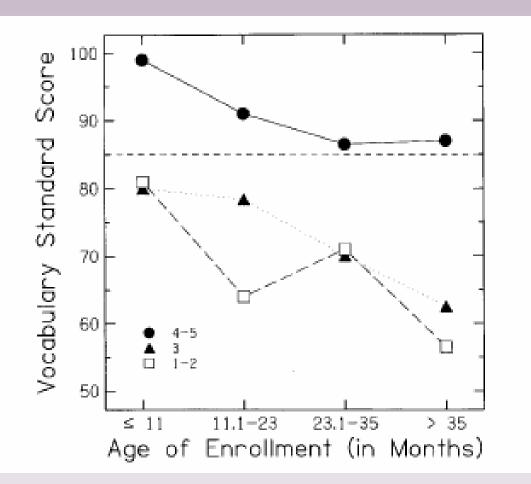
Face-to-face interaction with professionals – major importance

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

# Means and SDs of PPVT scores for subjects as a function of age of enrollment in intervention.



# Mean vocabulary scores plotted as a function of the two key variables, age of enrollment and family involvement ratings.



Moeller M P Pediatrics 2000;106:e43



# Before 6 months

Early Intervention services

Etiology and associated problems

Audiological follow-up

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





1/3 of children
with hearing
loss have
another major
disability!

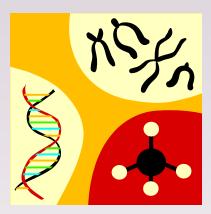


### **Genetic counseling**

- Future children recessive
- Other family members may be effected
- Etiology/diagnosis why?

### Syndromes

- Trisomy 21
- Usher Syndrome Retinitis pigmentosa
- Treacher-Collins cranio-facial abnormalities
- Jervell and Lange-Nielsen syndrome
  - Prolonged QT, sudden death



# EYE examination

Optimize vision – coexisting vision issues

 Common in both syndromic and non-syndromic causes

Assess findings of syndromes and etiology

Retinal findings of CMV and toxoplasmosis



# **ENT** Imaging

Status of cochlea, cochlear nerve and middle ear?

Imaging of the temporal bones – may help in etiology

### Abnormal in about 30% of patients

- More likely with asymmetric hearing impairments
- Abnormal architecture of the inner ear

### Most commonly large vestibular aqueduct

- Often progressive
- Trauma can make worse sports?
- MRI/CT scan ?age 8-9 months

### 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



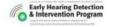
 Audiological evaluation of developmentally delayed or uncooperative children

### **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<br>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)<br>when a sound is presented to the ear. To conduct the test, a tiny probe is<br>placed just inside the baby's ear canal and a soft click is presented, a tiny<br>microphone measures the response produced by the baby's ear. The test is<br>quick (about 5 to 10 minutes), painless, and may be done while the baby is<br>sleeping or lying still. Thus, OAEs reflect the status of the peripheral auditory<br>system extending to the cochlear outer hair cells.   |
| Automated Auditory Brainstem<br>Response (AABR) | This screening test measures how the hearing nerve responds to sound. Clicks<br>are presented to the ear through a probe or soft earphones, and the neural<br>response is measured through three electrodes placed on the baby's head.<br>Automated ABR measurements reflect the status of the peripheral auditory<br>system, the eighth nerve, and the brainstem auditory pathway.  |
| Outpatient rescreening                          | <ul> <li>An outpatient rescreening can take place at any of the following:</li> <li>Hospital: Hospital screening protocols vary, and often include an outpatient screening should be based on the knowledge of how the inpatient screening would be based on the knowledge of how the inpatient screening, the outpatient screening would be based on the knowledge of how the inpatient screening, the outpatient screening would be based on the knowledge of how the inpatient screening, the outpatient screening must be conducted using 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 haves the hospital.</li> <li>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.</li> <li>Audiologist similar to the provider office, a rescreen may also take place at the audiologist office.</li> </ul> |
| Lost to follow up                               | For infant who did not pass newborn hearing screening, "lost to follow-up"<br>refers to a failure to receive the next step of treatment, be it rescreen or<br>comprehensive audiological evaluation.   |
| Lost to documentation                           | Failure to report the results from hearing screening, rescreening, diagnostic<br>services, and/or treatment services which are needed for comprehensive<br>surveillance and monitoring by END and the medical  |
| Lost to treatment                               | Failure for a child with an identified hearing loss to receive needed<br>therapeutic services and failure for families to receive needed information to<br>support decisions regarding treatment options.  |
| Medical home                                    | A model for providing high quality primary care that addresses and integrates<br>health promotion, acute care and chronic condition management in a<br>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<br>function, but showimpairment in the function of the auditory nerve.<br>Functional hearing can often be quite impaired and diagnosis and freatment<br>can be confusing and complicated.   |



#### 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 accur. Without the active assistance of the medical home the infant may be considered "lost" in the early hearing detection and intervention (EHDI) system, which undermines the potential 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 HOMES 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?

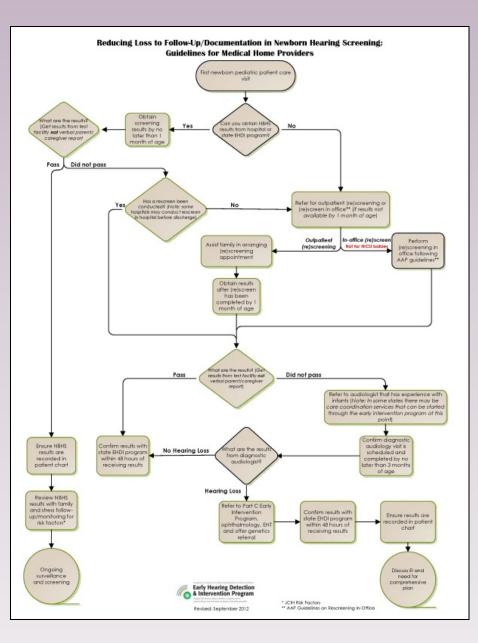
The following information outlines specific actions the medical home can take to reduce the percentage of infants who do not pass a newborn hearing screen who either do not receive follow up care or whom follow up is not reported back to the state EHDI programs. It is important to note that the actions 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<sup>14</sup> 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



### **AAP EHDI LTF/D Guidelines & Checklist**



#### 1-3-6 NEWBORN HEARING SCREENING CHECKLIST

| Patient Name:   |                                | tient DO     | B: Date of Visit:   |
|---|--------------------------------|--------------|---|
| INITIAL SCREENING (by no later than 1   | month of c                     | ige)         |   |
| Has the child had a newborn hearing screening?  | Yes                            | No⇔          | Schedule initial screen   |
| Did you obtain the test results from the screening<br>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<br>program?  | Yes                            | No ⇔         | Confirm results have been reported to state EHDI<br>program within 48 hours of receiving them.  |
| Have results been discussed with family?  | Yes                            | No⇔          | <ul> <li>For a child that passed, stress the importance of<br/>ongoing surveillance and risk factors*</li> <li>For a child that did not pass, discuss the need for<br/>follow-up and assist in arranging a rescreening</li> </ul>                 |
| Has a rescreening occurred (if the initial screen<br>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?  | Hospital                       | :            |   |
| <ul> <li>If hospital/outpatient center, when is the<br/>rescreening appointment?</li> <li>If conducted in office:</li> <li>Determine what screening eaupment was</li> </ul> | Office<br>Office<br>(specify): |              |   |
| <ul> <li>Determine what scheming equipment was<br/>used at the hospital.</li> <li>Follow the AAP office rescreening<br/>guidelines.</li> </ul>                              |                                |              |   |
|   | Date:                          |              |   |
| Did the child pass the rescreening?   | Yes                            | No⇔          | Send child to audiologist with pediatric expertise for<br>diagnostic evaluation.  |
| Are the results recorded in the patient chart?  | Yes                            | No ⇔<br>No ⇔ | Record results in patient chart.  |
| Have the results been discussed with the family?  | Yes                            | NO           | <ul> <li>For a child that passed, stress the importance of<br/>ongoing surveillance and risk factors*</li> <li>For a child that did not pass, discuss the need for<br/>follow-up and asist in arranging an audiological<br/>evaluation</li> </ul> |
| Have the results been reported?   | Yes                            | No⇔          | Confirm results have been reported to state EHDI<br>program within 48 hours of receipt  |
| BIAGNOSTIC EVALUATION (by no late   | er than 3 m                    | onths o      | f age)  |
| If the child did not pass the rescreening, was he/she   | Yes                            |              | No ♥ Refer to audiologist with  |
| referred to an audiologist with expertise in  | Provider:                      |              | expertise in pediatrics   |
| pediatrics?   | Date of Vis                    | sit:         |   |
| Were the results of the diagnostic test normal?   | Yes                            | No ⇔         | Discuss El and need for comprehensive plan  |
| Have the results been discussed with the family?  | Yes                            | No⇔          | <ul> <li>For a child that passed, stress the importance of<br/>ongoing surveillance and risk factors</li> <li>For a child that did not pass, discuss El and need for<br/>comprehensive plan</li> </ul>  |
| Have the results been reported?   | Yes                            | No ⇔         | Confirm results have been reported back to state EHD<br>program within 48 hours of receipt  |
| 6 EARLY INTERVENTION (by no later that  | n 6 month:                     | s of age     | 9   |
| If the child was aliagnosed with a hearing loss, was<br>he/she referred for early intervention and multi-<br>disciplinary evaluation?                                       | Yes<br>Date of vis             |              | No ⇒ Provide early intervention referral<br>and ophthalmology, and ENT,<br>offer genetics   |
| ONGOING SURVEILLANCE AND SCRE   | ENING                          |              |   |
| Continue to perform ongoing surveillance and screen   |                                | onset he     | aring loss -particularly those oblidien with risk factors   |
| services to benefit to Part Part And and and a clean  | - Gronue                       | of a GT 1 KG | on grow portionary more criticite twittine racios.  |

# Medical Home and LTF/D AAP EHDI Tools

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 Tools

Confirm results with state EHDI program within 48 hours

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

Ensure family is referred to local EI program

- Need to learn state reporting program
- Confirm appointments and notify state EHDI program
- refer to CDC EHDI Directory EHDI PALS
- 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 Tools

| Dedicated staff<br>person in the practice                                 | <ul> <li>Obtain all screening results</li> <li>Coordinate the education/support of families</li> <li>Relationship with State EHDI program</li> </ul>  |
|---|---|
| Provide education<br>and support to<br>families                           | <ul> <li>Hearing, speech, and language milestones</li> <li>Discuss and explain all test results, next<br/>steps, and importance of follow-up</li> <li>Confirm with family that follow-up<br/>appointments have been made and kept</li> <li>Help to arrange transportation and social<br/>service support</li> </ul> |
| Culturally competent<br>and health literate<br>appropriate<br>information | <ul> <li>Hands and Voices, Guide-By-Your-<br/>Side, NCHAM, etc.</li> <li>Educational options</li> </ul>   |

### **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: <u>http://www.infanthearing.org/status/cnhs.html</u>.

#### 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 officebased 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 (AAABR) 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 bables 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

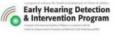
- It is best to have a quiet environment for office-based testing to minimize the risk of ambient noise interfering with the screening results.
- · Office personnel who perform the re-screening should be trained and experienced in screening infants and children.
- It is important that the infant is only 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.

✓ In some circumstances an AABR may be warranted to rule out auditory neuropathy.

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

### **NICU graduates**

# **TOP Trusted Sources**

- (1) Pediatricians (58%)
- (2) Friends and family (55%)
- (3) Evening news (39%)
- (4) Internet searches
   (38%)

- (5) Physician office (37%) ■
- (6) Web sites (33%)
- (7) Parenting books (32%)
- (8) Morning TV talk shows
   (31%)

- (9) Newspaper articles (28%)
- (10) Magazine articles
   (25%)



## How to Reach PCPs?

# Decide who you want to reach? Who is reachable?

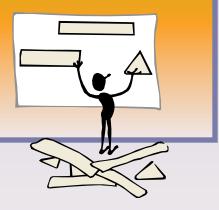


Stevenson and Biernath 2010, Lieser and Levine 2012, Texas EHDI Pilot Program 2011

# Can the Medical Home Reduce LTF/D?

# It's tough to make predictions, especially about the future.

Yogi Berra





### Find these resources at:

### http://**www.infanthearing.org**/ medicalhome/index.html

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



# Please type questions or comments in the chat box.

# This session will be posted on our EHDI website for future viewing.

Thank you for your participation!

# Are Confident People More Accurate?

|  |                    | moderate hearin | th bilateral mild-<br>g loss candidates<br>ear Implant? |
|--|--------------------|-----------------|---|
| talking to<br>rmanent<br>o is a<br>?   |                    | Yes             | Νο  |
| e you in t<br>with pe<br>bout wh   | Very Confident     | 87.3%           | 12.7%   |
| How confident are you in talking to<br>parents of a child with permanent<br>hearing loss about who is a<br>candidate for CI's? | Somewhat Confident | 73.8%           | 26.2%   |
| How cor<br>parents<br>hear   | Not Confident      | 69.7%           | 30.3%   |



### Did your training prepare you adequately to meet the needs of infants with permanent hearing loss?

|  | Yes<br>(n=383) | Unsure<br>(n=618) | No<br>(n=1056) |
|--|----------------|-------------------|----------------|
| Routinely refer the family of a child with permanent hearing loss to a geneticist.                     | 17.0%          | 9.7%              | 6.4%           |
| Believe hearing aids can be fit for children<br>0 to 3 months of age.                                  | 46.9%          | 38.8%             | 36.3%          |
| Believe infants with bilateral mild-<br>moderate hearing loss are candidates for<br>cochlear implants. | 18.3%          | 30.6%             | 27.8%          |
| Believe unilateral hearing loss affects speech and language development                                | 73.1%          | 73.0%             | 73.9%          |

# Years of practice with pediatric population

|  | <b>0-10 Years</b><br>(n=564) | <b>10-20 Years</b><br>(n=651) | <b>20-30 Years</b><br>(n=531) | <b>30+ Years</b><br>(n=300) |
|--|------------------------------|-------------------------------|-------------------------------|-----------------------------|
| Routinely refer the family of a child<br>with permanent hearing loss to a<br>geneticist.               | 9.0%                         | 10.9%                         | 7.7%                          | 9.3%                        |
| Believe hearing aids can be fit for children 0 to 3 months of age.                                     | 32.7%                        | 38.6%                         | 43.7%                         | 41.6%                       |
| Believe infants with bilateral mild-<br>moderate hearing loss are<br>candidates for cochlear implants. | 31.9%                        | 29.2%                         | 20.9%                         | 20.3%                       |
| Believe unilateral hearing loss<br>affects speech and language<br>development                          | 78.4%                        | 75.3%                         | 71.4%                         | 63.3%                       |

# What percentage of your practice is comprised of infants or children 0-5 years of age?

|   | <b>≤ 33%</b><br>(n=1096) | <b>34-65%</b><br>(n=637) | <b>≥ 66%</b><br>(n=357) |
|---|--------------------------|--------------------------|-------------------------|
| Routinely refer the family of a child with permanent hearing loss to a geneticist.                    | 6.8%                     | 11.6%                    | 13.7%                   |
| Believe hearing aids can be fit for children 0 to 3 months of age.                                    | 33.6%                    | 43.9%                    | 45.0%                   |
| Believe infants with bilateral<br>mild-moderate hearing loss are<br>candidates for cochlear implants. | 23.4%                    | 28.7%                    | 30.8%                   |
| Believe unilateral hearing loss<br>affects speech and language<br>development                         | 70.7%                    | 74.4%                    | 73.9%                   |

## Type of Provider

|   |       | diatrician | L) practice | 158710815t | natologist | 181GYM 2) | raction |
|---|-------|------------|-------------|------------|------------|-----------|---------|
|   |       | Fou        | phy otole   | - He       |            | NUTSe IS  | 1451    |
| FREQUENTY receive informaton from your state EHDI program?  | 13.3% | 7.3%       | 7.3%        | 14.3%      | 8.3%       | 8.9%      |         |
| COMPLETE trust in newborn<br>hearing screening results?   | 34.5% | 33.5%      | 21.2%       | 42.4%      | 33.3%      | 38.6%     |         |
| Believes that "Mother's age > 40<br>years" puts a child at increased<br>risk for permanent hearing loss | 14.5% | 23.3%      | 6.5%        | 29.9%      | 25.0%      | 26.1%     |         |
| Conducts in-office screening  | 26.7% | 22.2%      | 77.8%       | 24.6%      |            | 28.9%     |         |



## Type of Provider

|   | 2     | ediatrician<br>Fam | 2) Practice<br>IN Practice<br>Physician<br>Physician<br>Physician | In the logist | onatologist | DBIGINI 2)<br>NUTSER |
|---|-------|--------------------|---|---------------|-------------|----------------------|
| Routinely refer the family of a child with permanent hearing loss to a geneticist                     | 10.9% | 2.7%               | 27.1%   | 9.0%          | 0.0%        | 6.5%                 |
| Believe hearing aids can be fit for children 0 to 3 months of age                                     | 43.1% | 29.1%              | 47.9%   | 46.5%         | 36.4%       | 40.5%                |
| Believe infants with bilateral<br>mild-moderate hearing loss are<br>candidates for cochlear implants. | 30.0% | 23.3%              | 6.5%  | 29.9%         | 25.0%       | 26.1%                |
| Believe unilateral hearing loss<br>affects speech and language<br>development.                        | 75.2% | 71.7%              | 66.5%   | 58.2%         | 66.7%       | 82.6%                |



### **Type of Provider and Setting**

|  | Pediatrician | Family Prace | 0toler 1, 1, 1, 1, 2, 05, 05, 05, 05, 05, 05, 05, 05, 05, 05 | Nurse Praction |
|--|--------------|--------------|--|----------------|
| Conducts in-office hearing screening   | 27.1         | 23.1         | 78.9   | 30.6           |
|  | 17.2         | 27.8         | 84.2   |                |
| Routinely refers the family of a child with permanent hearing loss to a geneticist | 9.9          | 3.0          | 23.3   | 8.1            |
|  | 13.8         | 5.6          | 57.9   |                |
| Believes hearing aids can be fit   | 42.7         | 29.8         | 45.6   | 41.9           |
| for children 0-3 months of age   | 46.2         | 20.0         | 50.0   |                |
| Believe infants with bilateral mild-moderate hearing loss are                      | 30.5         | 24.0         | 7.8  | 24.3           |
| candidates for cochlear implants   | 10.3         | 16.7         | 0.0  |                |
| Believe that "Mothers age > 40<br>years" puts a child at increased                 | 15.0         | 23.0         | 32.8   | 21.6           |
| risk for permanent hearing loss  | 13.8         | 16.7         | 26.3   |                |

Private practice or community clinic (n=1,747) Medical School (n=81)



## Type of Provider

|   | 2     | ediatrician<br>Fam | 2) Practice<br>IN Practice<br>Physician<br>Physician<br>Physician | In the logist | onatologist | DBIGINI 2)<br>NUTSER |
|---|-------|--------------------|---|---------------|-------------|----------------------|
| Routinely refer the family of a child with permanent hearing loss to a geneticist                     | 10.9% | 2.7%               | 27.1%   | 9.0%          | 0.0%        | 6.5%                 |
| Believe hearing aids can be fit for children 0 to 3 months of age                                     | 43.1% | 29.1%              | 47.9%   | 46.5%         | 36.4%       | 40.5%                |
| Believe infants with bilateral<br>mild-moderate hearing loss are<br>candidates for cochlear implants. | 30.0% | 23.3%              | 6.5%  | 29.9%         | 25.0%       | 26.1%                |
| Believe unilateral hearing loss<br>affects speech and language<br>development.                        | 75.2% | 71.7%              | 66.5%   | 58.2%         | 66.7%       | 82.6%                |

