

# **Early Hearing Detection and Intervention (EHDI): The Role of the Medical Home**

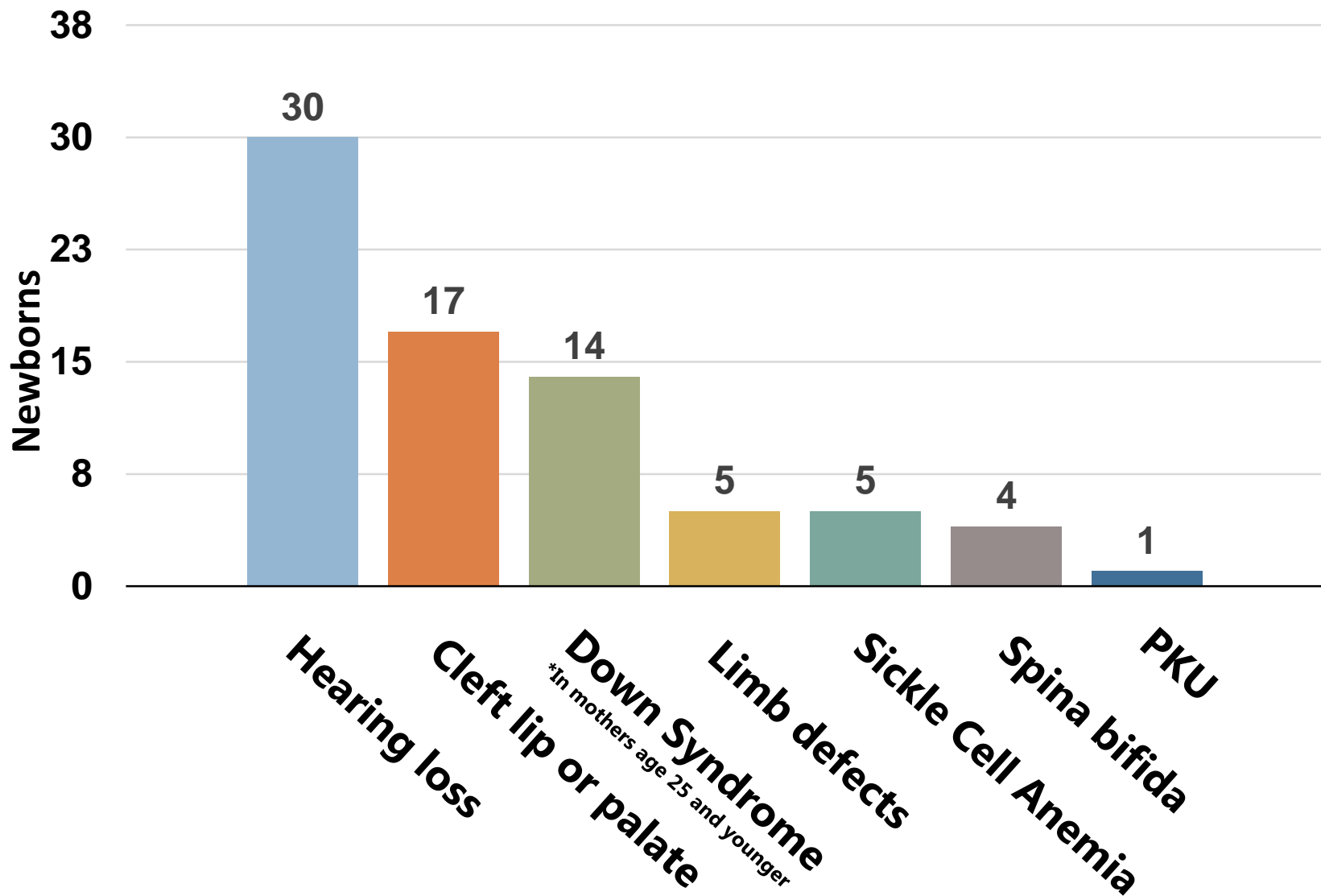
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A PRESENTATION FROM THE AMERICAN ACADEMY OF PEDIATRICS



# Comparison of Select Congenital Conditions

## Incidence per 10,000 of Congenital Conditions



# Early Hearing Detection & Intervention (EHDI) Program

## 1-3-6

## National EHDI Goals

- All infants will receive a hearing screening before **1** month of age
- Infants not passing the screening will receive appropriate audiologic and medical evaluation before **3** months of age
- All infants identified as deaf or hard of hearing will begin receiving early intervention services before **6** months of age

### Three Key Components of Early Hearing Detection & Intervention Programs



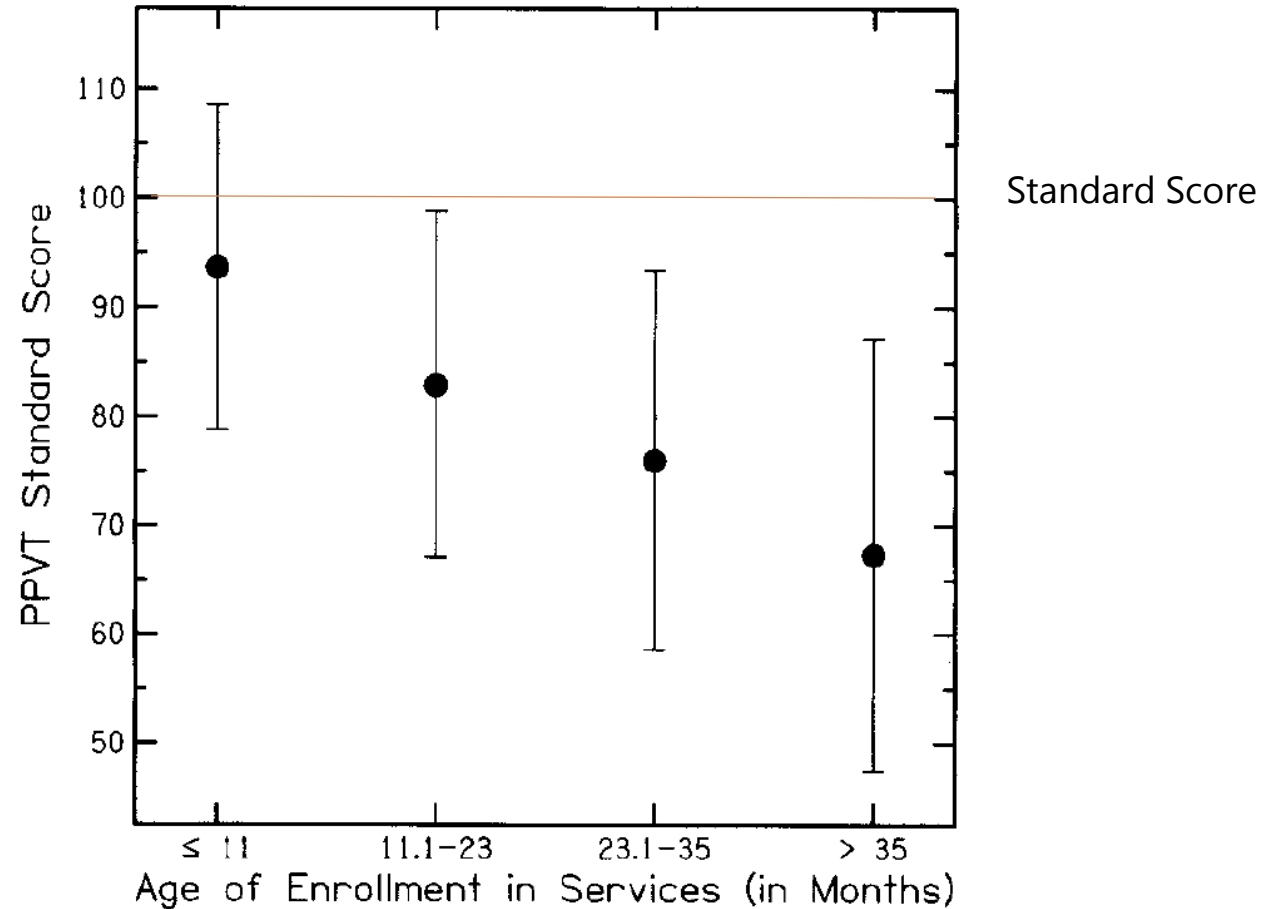
# Developmental Emergency

An infant who does not pass his/her newborn hearing screening has a potential developmental emergency.

However...

Early identification of hearing loss can result in positive language outcomes for children who are Deaf or Hard of Hearing.

## Effects of Age of Identification on Language Development



Moeller, 2000

# State EHDI Programs



**EHDI:**

**A Public Health and Clinical  
Medicine Partnership**

# State EHDI Programs



## State EHDI Goals

- Every state and territory in the United States has now established an Early Hearing Detection and Intervention (EHDI) program.
- All 50 states and the District of Columbia have a law, regulation, or documented legislative intent about hearing screening and hearing screening guidelines.
- EHDI program staff are responsible for creating, operating, and continuously improving a system of services which assures that the national EHDI goals are met.
- State EHDI Laws and Regulations  
[http://www.aap.org/en-us/Documents/pehdic\\_ehdi\\_%20state\\_requirements.pdf](http://www.aap.org/en-us/Documents/pehdic_ehdi_%20state_requirements.pdf)
- NCHAM State Resource Page  
[http://www.infanthearing.org/states\\_home/](http://www.infanthearing.org/states_home/)

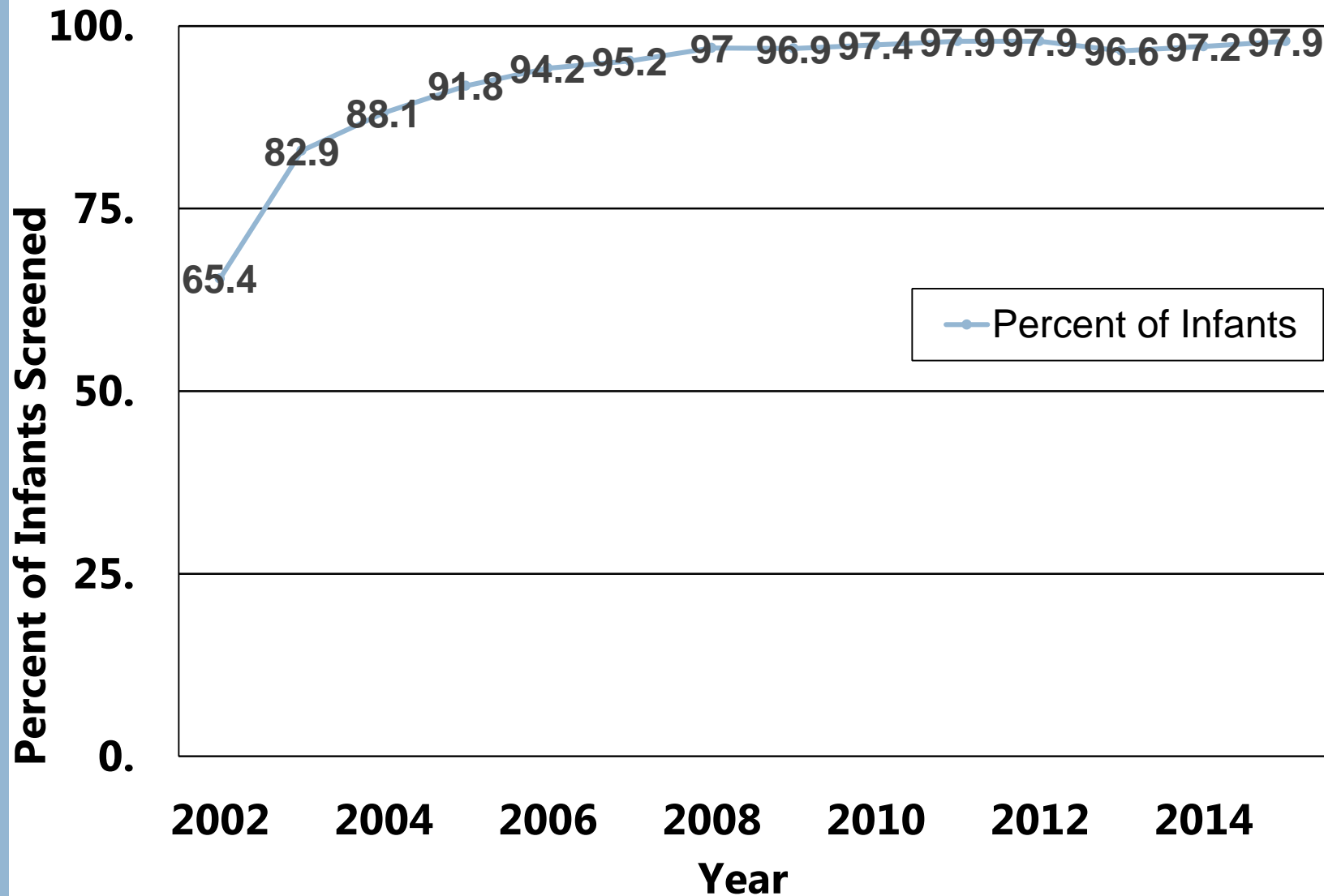
# EHDI Program Components

- Universal Newborn Hearing Screening
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Care Coordination
- Tracking and Data Management

# National EHDI Data

# Universal Newborn Hearing Screening

## Percent of Infants Receiving Hearing Screening: 2002-2014

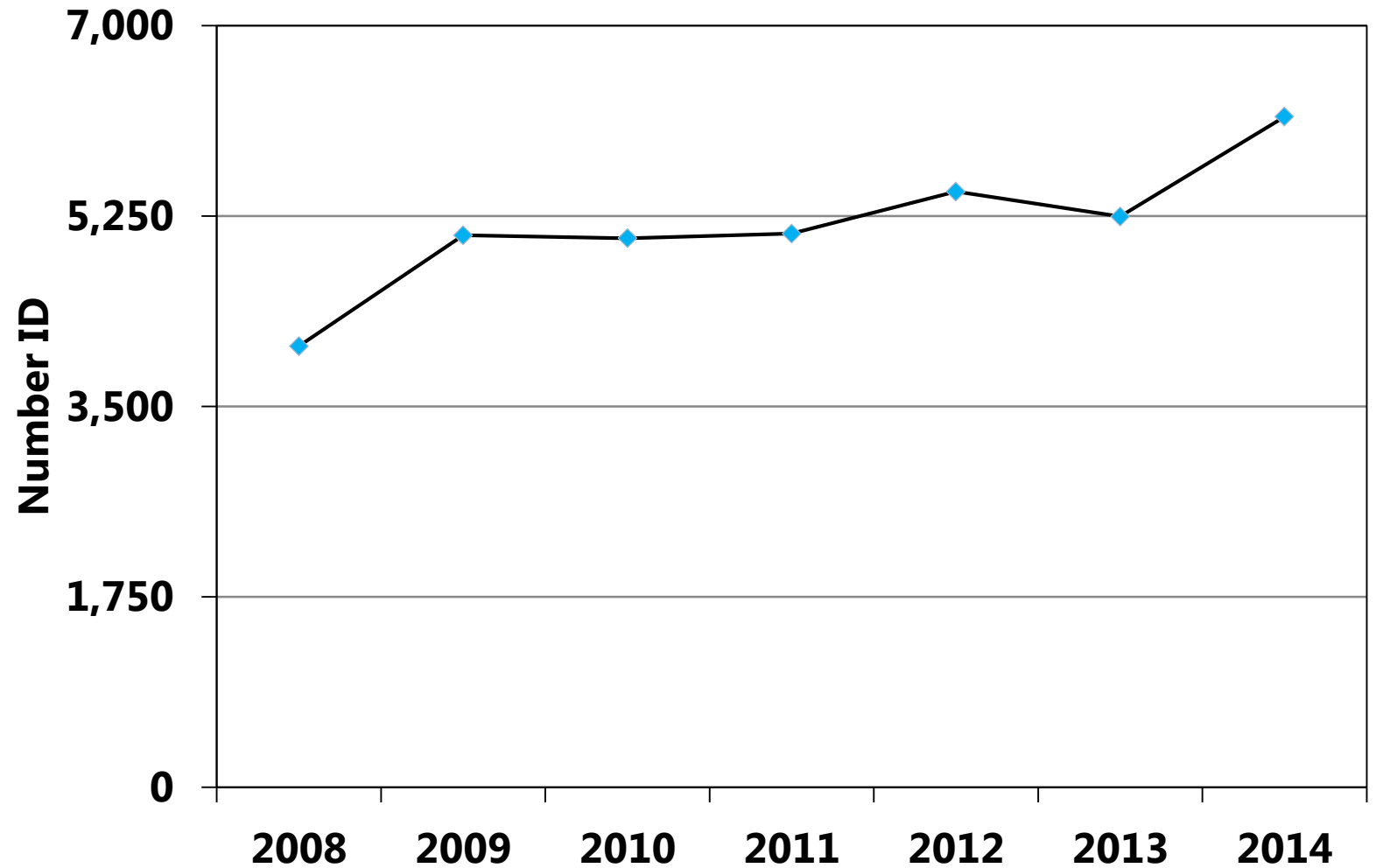




## National EHDI Data

### Incidence of Children who are Deaf or Hard of Hearing

#### Infants Identified as Permanently Deaf or Hard of Hearing, 2008 – 2014 (*Total = 36,145*)



Source: CDC EHDI Hearing Screening and Follow-up Survey (2016)

# National EHDI Data

## Outcomes of Screening and Diagnosis



## 2014 National CDC EHDI Data

- Births: 3,963,042
- Screened: 3,877,851 (97.9%)
- Not Passing Screen: 63,341 (1.6%)
- Diagnosed:
  - Normal Hearing: 30,309 (47.9%)
  - DHH: 6,163 (9.7%)
- No Diagnosis: 26,869 (42.4%)

# National EHDI Data

## 1-3-6 Goals



## 2014 National CDC EHDI Data

- % Screened: **97.9%** (n=3,963,042)
- Prevalence of children who are deaf/hh: **1.6 per 1,000** screened (Range 0.6-3.3 per 1,000)
- % of those identified receiving Early Intervention: **64.9%** (n=4,000)
  
- % Screened before 1 month of age: **96.1%** (n=3,724,684)
- % Diagnosed before 3 months of age: **71.3%** (n=26,002)
- % Receiving Intervention before 6 months of age: **67.9%** (n=2,717)
  
- % Loss to Follow-up or Documentation: **25.5%** (n=16,168)
- % Loss Due to Parent Unresponsiveness: **8.9%** (n=5,651)

# Common Newborn Hearing Screening Tests

## OAE versus AABR

- The two screening methods are reliable and can be used separately or together based on:
  - Whether the baby needs intensive (AABR) or routine newborn care (OAE and/or AABR)
  - The hospital's choice
  - State EHDI guidelines
- Both OAE and AABR may miss very mild hearing loss and frequency-specific hearing loss. OAE will miss auditory nerve or auditory brainstem pathway dysfunction, such as auditory neuropathy spectrum disorder.
- Babies who do not pass on the first OAE screen can be given a second screen using either an OAE or the AABR.
- Know your hospital's screening policies

# The Role of Medical Home

## Why Do Kids Fall Through the Cracks?

- Inconsistent screening techniques
- Loss to follow up after screening
- Parental refusal to follow up on screening
- Lack of access to audiology follow up
- Inconsistent quality of diagnostic evaluation
- Lack of communication with state EHDI program
- False negatives for babies with mild loss
- Lack of recognition of risk for progressive hearing problems

# The Role of Medical Home

## Early Hearing Detection and Intervention

- Creating a medical home plays a key role in the success of EHDI programs.
- A medical home can help families understand the EHDI process.
- The medical home ensures that appropriate and timely steps are taken to identify children who are deaf/hh and get them into an early intervention program.
- The medical home serves as the primary coordinating entity which can help significantly reduce loss to follow-up/documentation.

# The Role of Medical Home



## If there is any suspicion that an infant is deaf or hard of hearing...

- Do listen to parents concerns
- Assure prompt follow-up with rescreens and diagnostic evaluations
- Make sure diagnostic evaluations are done by an audiologist who has experience with infants
- Set up electronic medical record (EMR) system to include results of auditory screening
- Flag all patient charts for children that require follow-up for hearing screens
- Flag all patient charts for children that are at risk for late onset hearing loss

# The Role of Medical Home



## What about risk factors?

- Any Parental Concern
- Family history of hearing loss
- NICU Graduates
- Intrauterine Infections
- Craniofacial, Anomalies
- Genetic Conditions Associated with HL
- Neurodegenerative Disorders
- Serious Head Trauma, Child Abuse
- Meningitis
- Chemotherapy



# The Role of Medical Home



## What about risk factors?

- Every family must be asked about risk factors
- Develop an individualized plan for every child with risk factors
- All children, regardless of risk factors, must have appropriate developmental surveillance as per Bright Futures and an ideologic diagnostic evaluation if concern arises

# The Role of Medical Home



**All screening results, risk factors and surveillance plans MUST be discussed with the family and documented in records!!**

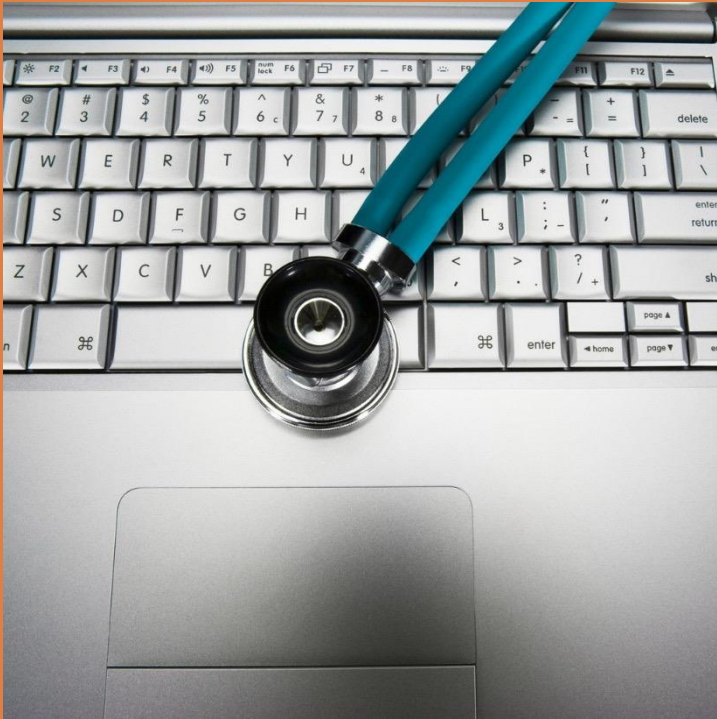
# The Role of Medical Home



## Infants Identified As Deaf or Hard of Hearing

- Address the family's concerns
- Ensure the family is seeing an experienced pediatric audiologist
- Refer the family to appropriate specialists
  - Otolaryngology, Genetics, Ophthalmology
- Help the family obtain early intervention services and coordinate care

# Tracking & Data Management

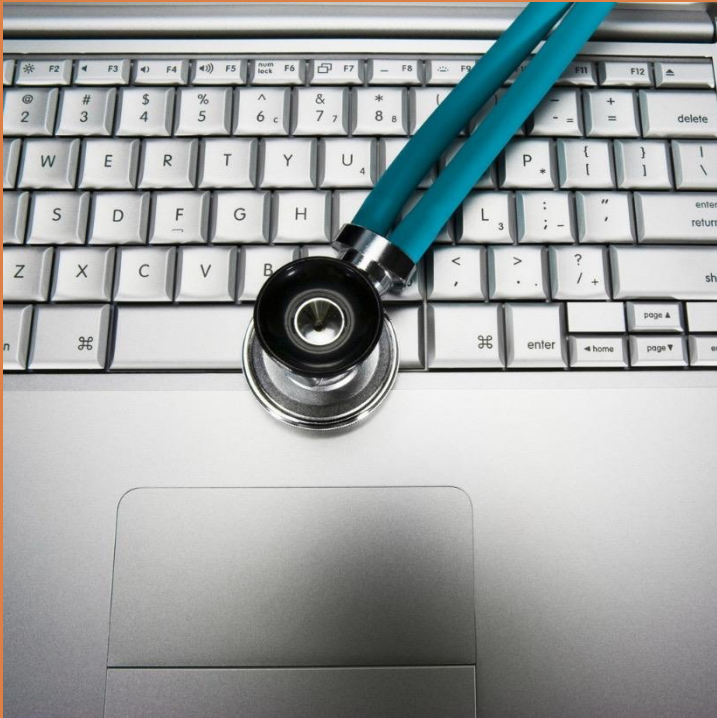


## The success of these programs depends on reporting, tracking, and follow-up!

According to the Joint Committee on Infant Hearing, information management is used to:

- Improve services to infants and their families
- Assess the quality and timeliness of screening, evaluation, and enrollment into intervention
- Facilitate collection of demographic data on neonatal and infant hearing status

# Tracking & Data Management



## The Role of the Medical Home in Tracking and Reporting

- Learn how information is sent to EHDI program in your state and what responsibilities you may have
- If conducting an in-office screen, you **must** report the results directly to the state EHDI program
- AAP State EHDI Laws and Regulations Resource:

[http://www.aap.org/en-us/Documents/pehdc\\_ehdi\\_%20state\\_requirements.pdf](http://www.aap.org/en-us/Documents/pehdc_ehdi_%20state_requirements.pdf)

# Assuring Follow Up

## Increasing Follow Up Rates After a Screen That Is Not Passed

- The primary care physician plays a key role in helping to increase the number of babies receiving follow up:
  - Emphasizing to parent the need for F/U
  - Referring to qualified audiologists
  - Creating a system to assure follow up occurs and results are received in your office
- LTF/D resources available under the Loss to Follow-up heading at the AAP EHDI web page

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



# Conducting an In-Office Hearing Screening or Re-screening



## Key Highlights

- In general, medical homes should NOT conduct the initial newborn hearing screening and re-screening should be limited to OAE screening
- It is very important that the medical home know what screening equipment is used at local birth facilities
- If you are conducting a re-screening, you are obligated to report the results to the state EHDI program
- Additional guidelines available at:

<http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/NBHSRescreening1%200414.pdf>



# Diagnostic Evaluations

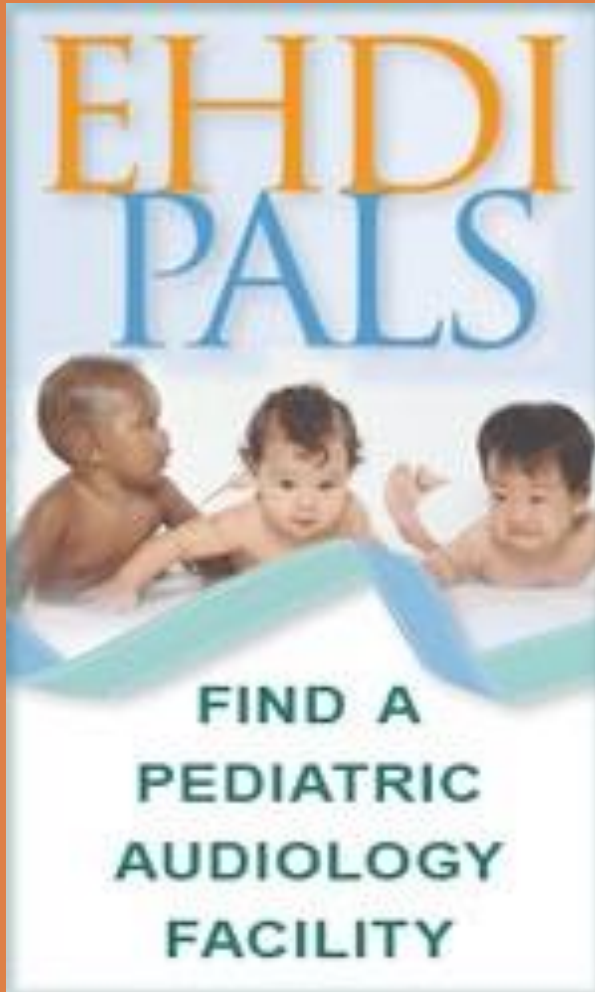
- Timely and appropriate diagnostic and intervention services are associated with positive communicative outcomes
- If diagnostic audiologic assessment is indicated, complete before 3 months of age
- The diagnostic audiologic evaluation should be performed by a pediatric audiologist
- The audiologist should perform a series of tests, to determine:
  - If a hearing loss exists
  - Type
  - Degree
  - Configuration of the loss

# Audiology Intervention



- Hearing aids, if needed, may be prescribed at any age, and should be fit before 6 months of age
- Routinely monitor the effectiveness of hearing aids
- Routine assessment by audiologist after hearing aids are fit should be completed and new ear molds or hearing aids prescribed if needed
- Hearing should be retested on a regular basis to assess levels of hearing change and to identify any issues

# EHDI – PALS



## Early Hearing Detection & Intervention – Pediatric Audiology Links to Services

- EHDI-PALS is a web-based link to information, resources, and services for children who are deaf/hh
- A national web-based directory of facilities that offer pediatric audiology services to children less than five years of age
- The medical home can use EHDI-PALS to help refer families to the most appropriate diagnostic facility and services

<http://www.ehdipals.org/>

# Specialty Referrals

## Otolaryngology

- Assess integrity of ear canal and middle ear
- Order appropriate diagnostic testing such as temporal bone CT, MRI, etc
- Discuss possible surgical interventions
- Counsel family and follow for success of intervention

## Genetics

- Evaluate for possible genetic causes of hearing loss
- Counsel family and patient

## Ophthalmology

- Assess integrity of visual system
- Evaluate for visual problems known to be associated with hearing changes

# Early Intervention



- Early Intervention (EI) services are provided to children and families under the Individuals with Disability Education Act (IDEA) of 2004, Part C
- All families of infants who are deaf/hh, regardless of degree or bilaterality/unilaterality, should be considered eligible for early intervention services
- Children identified as deaf/hh who begin services before 6 months old develop language (spoken or signed) on a par with their hearing peers (Yoshinaga et al., 1998)
- Communication between EI and your office is essential
- Access several early intervention tools by visiting [www.infanthearing.org/earlyintervention/](http://www.infanthearing.org/earlyintervention/)

# Family Support



## Physician and Family Collaboration

- Your primary role if a diagnosis is made is to provide support and coordination!
- Importance of peer support
- Identify and celebrate progress with a family
- Families feel supported by professionals when they perceive the relationship to be a collaborative partnership built on trust
- This process takes time and involves mutual respect, honest and clear communication, understanding, and empathy

# Family Support



## Addressing Parental Concerns:

- Overcoming shock and denial
- Outlining next steps
- Giving hope
- Establishing a partnership

# Do Nots



## In a medical home environment, you can never:

- Tell a parent that a screen not passed is “probably nothing”
- Ignore a parent’s concern about hearing
- Never say “It can’t be his hearing. Remember he passed his screen.”
- Feel that after you’ve referred your job is done



# Family Support Resources



## Organizations Supporting D/HH Individuals and Their Families

- Hands & Voices

<http://www.handsandvoices.org/>

- Alexander Graham Bell Association

<http://www.listeningandspokenlanguage.org/>

- Family Voices

<http://www.familyvoices.org/>

- American Society for Deaf Children

<http://deafchildren.org/>

# Helpful Resources from the National Center for Hearing Assessment and Management (NCHAM)

- NCHAM Interactive Web-based Newborn Hearing Screening Training Curriculum
- Educational and Training Videos
- NCHAM EHDI eBook: A Resource Guide for Early Hearing Detection and Intervention
- Slideshow Presentations

\*All materials can be found on the NCHAM website under the “Resources” heading: [http://www.infanthearing.org/resources\\_home/](http://www.infanthearing.org/resources_home/)

# Useful Web sites



- American Academy of Pediatrics (AAP) EHDI page  
<http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx>
- Joint Committee on Infant Hearing (JCIH)  
<http://www.jcih.org/>
- Boys Town National Research Hospital  
<http://www.boystownhospital.org/>

# Acknowledgements

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