FOLLOW-UP IN THE MEDICAL HOME: FINDINGS FROM NEW YORK PRIMARY CARE PROVIDERS SURVEY

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2011 Early Hearing Detection Intervention Conference
Universal Newborn Hearing Screening
Medical Home
Diagnostic Audiology
Early Intervention
Family Support
Tracking and Data Management
THE MEDICAL HOME: A CONCEPT RATHER THAN A BUILDING

- Accessible
- Family-centered
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally Effective
Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers

**Newborn Screening Birth**
- Identify a Medical Home for every infant
- Hospital-based Inpatient Screening (CAE/AABR) (only AABR or ABR if NICU > 5 days), all results sent to Medical Home

**Screening Completed Before 1 Month**
- **Home Births**
  - Failed Screen, or Missed, or Incomplete
  - Pass
  - Outpatient Re-Screening (CAE/AABR) all results sent to Medical Home and State EHDI Program

**Diagnostic Evaluation Before 3 Months**
- Pediatric Audiologic Evaluation with Capacity to Perform:
  - OAE*
  - ABR*
  - Frequency-specific tone bursts
  - Air & bone conduction
  - Sedation capability (only needed for some infants)
- Audiolist Reports to State EHDI Program:
  - Every child with a permanent hearing loss, as well as all normal follow-up results
  - Refer to IDEA* Part C
- Coordinating agency for early intervention
- Team Advises Family About:
  - All communication options; different communication modes; assistive listening devices (hearing aids, cochlear implants, etc); parent support programs
- Medical & Otologic Evaluations:
  - To recommend treatment and provide clearance for hearing aid fitting
  - Pediatric Audiology
  - Hearing aid fitting and monitoring

**Intervention Services Before 6 Months**
- Continued enrollment in IDEA* Part C (termination of Part C at 3 years of age)
- Referrals by Medical Home for specialty evaluations, to determine etiology and identify related conditions:
  - Otolaryngologist (required)
  - Ophthalmologist (recommended)
  - Geneticist (recommended)
  - Developmental pediatrician, neurologist, cardiologist, nephrologist (as needed)
- Pediatric audiology
  - Behavioral response audiometry
  - Ongoing monitoring

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


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

February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)
CHALLENGES TO MEDICAL HOME

- Low incidence of severe hearing loss
- Lack of physician education on all aspects
- Different terminology
- Success of UNHS – misconceptions
- Getting newborn results
- Retesting in office
- Family support
- Working with EI
- Working with community agencies
- Time constraints and financial constraints
PURPOSE OF THE SURVEY

- Identify what primary care providers (PCPs) do in their practices related to newborn hearing screening, follow-up and reducing loss to follow-up

- Identify PCPs attitudes and knowledge regarding newborn hearing screening

- Identify rescreening practices in the Medical Home

- Identify barriers and strategies for engaging PCPs in newborn hearing screening
SURVEY DESIGN

- Collaboration between EHDI and AAP
- Based on Pediatrics 2006 and DocSurvey questions from EHDI conference 2010 (CDC)
- "Pediatric Primary Care Physicians' Practices Regarding Newborn Hearing Screening". Ross, Danielle. In press.
SURVEY RESULTS

- General questions (14)
- Specific questions for PCPs who stated that they conduct hearing screening in their office (4)
- Demographic questions (10)
- SurveyMonkey™
- Survey sent out by American Academy of Pediatrics (AAP) District II (New York) to AAP and American Academy of Family Practitioner members
SURVEY RESULTS

- 160 responses received
- 150 (94%) responded that they are currently practicing medicine with children under the age of 3 years

Years of practicing with a pediatric population
- Median: 21 years (n=128)
- 0-5 years: 13%
- 6-10 years: 9%
- 11-20 years: 26%
- 20+ years: 52%

Years since residency
- Median: 21 years (n=127)
SURVEY RESULTS

Type of Practice

- 88% Pediatrician
- .7% Family Practice Physician
- 3.6% Neonatologist
- 8% Resident

Practice Setting

- 62% Private Practice
- 13% Hospital Setting
- 10% Community Health Centers
- 6.5% Medical School or Parent University
- 8% Other
RESULTS - DEMOGRAPHICS

Practice Type
- 10% Individual Practitioner
- 37% Group of 2-5 Practitioners
- 33% Group of greater than 5 Practitioners
- 16% Health Care Center
- 4% Other

Practice Location
- 32% Urban (inner city)
- 19% Urban (not inner city)
- 6% Small Town
- 37% Suburban
- 6% Rural
RESULTS - DEMOGRAPHICS

- Each MD sees a median of 50 patients a week
- 50% (median) of children are under 5 years
Children with Hearing Loss in Past 3 Years

N = 152 children

- 76 children (0-2 years)
- 52 children (3-5 years)
- 25 children (6+ years)
FAILED HEARING SCREEN – PAST YEAR

N = 153

- 37% in 0 - 2
- 35% in 3 - 9
- 27% in 10 +

- Pink: 75 - 100
- Yellow: 25 - 50
- Blue: 10 - 20
- Green: 6 - 8
- Brown: 5
- Orange: 3 or 4
- Red: 2
- Black: 1
- Gray: 0
20% of MDs still receive results 80% or less of the time
HOW DO YOU GET RESULTS?

- Other (newborn chart): 20.9%
- Written report - family: 53.4%
- Family verbal report: 35.8%
- Call hospital: 19.6%
- Hospital sends: 54.7%
IF YOU CAN’T GET RESULTS?

- Other: 21.7%
- Observe development: 27.5%
- Counsel parents: 17.5%
- Refer for screening: 52.5%
- Office screening: 20.8%
CHALLENGES FACED IN CHECKING FOR RESULTS

- Parents report/responsibility: 34%
- No time: 9.2%
- Hospital does it: 29.4%
- No charting procedure: 16.8%
- No mechanism/difficulty: 42%

Percent
WHAT PERCENT WHO FAIL GET RETESTED?

- N = 144
- 92% of MDs said 90% and above were retested
- 8% said 85% or less
## FAILED SCREEN – WHAT DO YOU DO?

<table>
<thead>
<tr>
<th>Action</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>El referral</td>
<td>10.9</td>
</tr>
<tr>
<td>Office f/u</td>
<td>27.9</td>
</tr>
<tr>
<td>Audiological</td>
<td>82.3</td>
</tr>
<tr>
<td>Contact parent</td>
<td>34.6</td>
</tr>
<tr>
<td>Contact hospital</td>
<td>12.2</td>
</tr>
<tr>
<td>File results</td>
<td>47.6</td>
</tr>
</tbody>
</table>

**Percent**
AUDIOLOGICAL/RESCREENING AFTER FAILED NEWBORN SCREEN

- F/u with testing facility: 46.3%
- F/U with parent: 75.8%
- Staff make appt: 48.3%
- Give parents info: 64.4%
25% (38/150) of MDs rescreen newborns in office

About 50% of MDs are able to screen hearing in their offices.
26/28 responded that office rescreening contributed positively to quality of care!
TO WHOM DO YOU REPORT OFFICE RESCREENS?

- Parents: 67%
- Hospital: 21%
- State EHDI: 12%
IF NEWBORN DID NOT GET SCREENED?

- Other: 9%
- Observe development: 23.9%
- Refer parents: 38.1%
- Screening referral: 72.4%
- Office screen: 23.1%
FAILED SCREEN AND RE-SCREEN - REFERRALS

Green = JCIH recommendations
RISK FACTORS – WHEN TO REFER FOR AUDIOLOGICAL?

- **Developmental concerns**: 71.2%
- **Family concerns**: 63.6%
- **Every 6 mos**: 18.2%
- **By 24-30 mos**: 57.6%
- **Other**: 5.3%
### AAP/JCIH RISK FACTORS FOR HEARING LOSS - 2007

**TABLE 3** American Academy of Pediatrics Joint Committee on Infant Hearing Year 2007 Position Statement: Risk Indicators Associated With Permanent Congenital, Delayed-Onset, and/or Progressive Hearing Loss in Childhood

<table>
<thead>
<tr>
<th>Risk Indicator</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Caregiver concern regarding hearing, speech, language, or developmental delay.</td>
</tr>
<tr>
<td>2</td>
<td>Family history of permanent childhood hearing loss.</td>
</tr>
<tr>
<td>3</td>
<td>Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO*, assisted ventilation, exposure to ototoxic medications (gentamicin and tobramycin) or loop diuretics (furosemide/Lasix), and hyperbilirubinemia that requires exchange transfusion.</td>
</tr>
<tr>
<td>4</td>
<td>In utero infections such as CMV*, herpes, rubella, syphilis, and toxoplasmosis.</td>
</tr>
<tr>
<td>5</td>
<td>Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies.</td>
</tr>
<tr>
<td>6</td>
<td>Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.</td>
</tr>
<tr>
<td>7</td>
<td>Syndromes associated with hearing loss or progressive or late-onset hearing loss*, such as neurofibromatosis, osteopetrosis, and Usher syndrome; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielsen.</td>
</tr>
<tr>
<td>8</td>
<td>Neurodegenerative disorders*, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome.</td>
</tr>
<tr>
<td>9</td>
<td>Culture-positive postnatal infections associated with sensorineural hearing loss*, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis.</td>
</tr>
<tr>
<td>10</td>
<td>Head trauma, especially basal skull/temporal bone fracture* that requires hospitalization.</td>
</tr>
<tr>
<td>11</td>
<td>Chemotherapy*.</td>
</tr>
<tr>
<td>12</td>
<td>Recurrent or persistent otitis media for at least 3 months.</td>
</tr>
</tbody>
</table>

Risk indicators that are marked with * are of greater concern for delayed onset hearing loss. ECMO indicates extracorporeal membrane oxygenation; CMV, cytomegalovirus.

PRIMARY SOURCES OF INFORMATION

- Conferences: 19%
- Research Literature: 25%
- Pediatricians/AAP: 21%
- CDC/National EHDI: 18%
- State EHDI: 12%
- Chapter Champions: 2%
- Other: 3%
SUMMARY

- Office rescreening
- Lack of experience with HL and failed screens
- Parent/doctor relationship
- Parent responsibility
- Difficulty in obtaining results
- MD knowledge
- How to reach the Medical Home?
CONTINUE PARTNERSHIP BETWEEN AAP DISTRICT II AND NYS DOH EHDI PROGRAM

- Develop a strategic plan to increase adherence to newborn screening regulations

- Begin communication to stimulate sustainable regional efforts to support increased adherence to the AAP recommendations for infants with hearing loss within a medical setting

- On-line survey to determine the best way for pediatricians to learn more about newborn hearing
CONTINUE PARTNERSHIP BETWEEN AAP AND DISTRICT II AND NYS DOH EHDI PROGRAM

- Conduct focused advisory group meetings of regional pediatric providers to determine methods of training would be best for pediatricians