PROGRESS in identification of hearing loss in children!!

- In 1993, only 3% of babies received a newborn hearing screening
- National mandate in 2000 required all states to provide hearing screenings to newborns.
- In 2012, 96-97% of babies received a newborn hearing screening
- Average age of identification:
  - 1980s: 30 months
  - 2003: 6 months
  - 2008: 3 months (White/NCHAM, 2008)
- This is a stable statistic
EHDI Goals and Basics

• Primary objectives of EHDI
  – Identify children as deaf and hard of hearing as early as possible
  – Enhance their development and opportunities for success through appropriate programming and intervention
  – Provide ongoing support to families

EHDI Goals and Basics ...(as you know)

• 1-3-6!!
  – Screen by 1 month
  – Diagnose by 3 months
  – Early intervention by 6 months

Overview of Indiana EHDI
IN EHDI System and Administration

• Indiana State Department of Health
  – Division of Maternal and Children’s Health
  • Genomics and Newborn Screening
    – EHDI Program

• Funding
  – Indiana state government (Director only)
  – CDC Grant
  – HRSA Grant

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EHDI System and Administration

• EHDI Staff
  – Director-Rebekah Cunningham, Ph.D.
  – Follow-Up Coordinator-Alyssa Rex, Au.D.
  – 2 EHDI Parent Consultants
  – 7 Regional Consultants (Audiologists)
  – Guide By Your Side Director
  – 10 GBYS Parent Guides
  – Support staff

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EHDI in Indiana
Identification, diagnosis and intervention of hearing loss

- Hospitals
- Newborn hearing screenings
- 102 facilities

- Health care professionals
  - Physicians, audiologists, SLPs

- Agencies
  - First Steps, Hear Indiana, Indiana Hands and Voices, Maternal and Child Health (MCH), ISDH, CDHHE

- Parents and families
  - Support and education
EHDI Process

- 80,000 babies born in Indiana each year
- Birthing centers use AABR (84%) and OAE (16%)
- Monitor hospital screening methods
- Provide follow up support and monitoring for babies who do not pass newborn hearing screenings and those at risk for hearing loss
- Provide support for ongoing interventic

Follow-up Coordinator-Alyssa Rex

- Completes data for CDC Annual Survey
- Follow up on approximately 10-20 new identifications of hearing loss per month
- Monthly reporting technical assistance and reports to hospitals and consultants
- New user screening/reporting training.
- Follow up on babies who pass with risk factors:
  - exposure to maternal infection (CMV, herpes)
  - craniofacial anomalies
  - jaundice
  - family history of congenital hearing loss

Parent Consultant

- EHDI Parent Consultant is alerted about babies that do not pass and contacts the families to assist with follow-up, and sends a letter to the family and to the PCP also contacts parent after diagnosis to provide support.
- Each month, the Parent Consultants:
  - 250 phone calls to parents
  - 150 calls to physician offices
  - 45 calls to audiologists
  - 30 calls to hospitals
  - >400 letters sent
Regional Consultant’s role

• 6 audiologists cover 8 regions
  – Provide training and support to hospital screening programs and audiologists (when necessary)
  • Two face-to-face visits per year 80%+ of the hospitals annually
  • Monitor hospital Monthly Summary Report (MSR) performance
• Contribute with Director and F/U Coordinator in creation/modification of hospital screening guidelines and DAE protocols (ie: revising Best Practices for Pediatric Audiology Services and Risk Factors reported and monitored)

After diagnosis of hearing loss

• PCP receives Physician Tool Kit
  – The letter, a survey, PCP-Med Home Care Management, Resources, PCP Care Plan, and GBYS insert
• Parent is contacted by a Guide by your Side parent to offer ongoing support to the family.
• Indiana’s parent guides have a hard of hearing child and have a variety of backgrounds:
  – Spanish-speaking
  – Amish and homebirth communities
  – Unilateral hearing loss
  – Cochlear implants
  – Hearing aids

Guide By Your Side

• Program of Hands and Voices and EHDI
• Guides are specially trained parents of deaf or hard of hearing children
• Provide unbiased support to families, from the perspective of someone who has walked a similar path in their demographic area
• Connect families to support organizations and assist them into Early Intervention
The role of the child’s audiologist

- Diagnostic testing of babies referred through UNHS using evidence-based practice and appropriate diagnostic testing procedures
- Report diagnostic test results to ISDH through use of the DAE form, regardless of hearing status.
- Work with PCP/pediatrician and family so that coordination of care occurs.

So how are we doing in IN?
PRELIMINARY 2015 DATA
**EHDI Successes**
- Improved accuracy and reporting (direct data entry)
- Increased timeliness of data sharing, contacting families, PCPs, audiologists, etc. through direct data entry and alerts/texting families has improved contact.
- Improved physician education to help improve the loss to follow up babies.
- Quarterly newsletter to improve awareness of EHDI.
- Improved collaboration by midwives with loaner equipment
- Organized an advisory committee to improve program
- Provide newborn hearing screening equipment on a loaner basis to 5 hospitals and audiologists each year through a separate grant

**Goals for EHDI**

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<tr>
<th>Improve collaboration with nurse midwives and provide physician education</th>
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<tr>
<td>- Provided loaner equipment to 4 midwife groups to start providing newborn hearing screenings</td>
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<tr>
<td>- Presented at state midwife conference</td>
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<td>- Physician conferences</td>
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<tr>
<th>Improve training and collaboration with Indiana pediatric audiologists</th>
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<tr>
<td>- Pediatric conference July</td>
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<td>- Newsletter</td>
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<td>- Regional Consultants</td>
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<td>- Revising Best Practice Guidelines</td>
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<tr>
<th>Improve monitoring and access of ongoing services for hard of hearing children: “6” goal</th>
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<tr>
<td>- Improve communication with audiologists in Indiana</td>
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<td>- First Steps interactions</td>
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<td>- Parent consultants</td>
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<th>Reduce “loss to follow up” numbers</th>
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<tr>
<td>- Improve communication with families/physicians/auds to obtain results</td>
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<tr>
<td>- First Steps interactions</td>
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**How can we help you?**
**How can you help us?**
- Haapi program [www.haapindiana.org](http://www.haapindiana.org)
- Contact us for resources regarding hearing loss in children
- Connect families to Guide by your Side for support
- Help improve communication with us regarding children identified with hearing loss
Contact
www.hearing.in.gov

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