What is EHDI?
(Early Hearing Detection & Intervention)

- National and state-based programs
- Comprehensive, coordinated system of support services for infants with hearing loss and their families.
- Goals:
  - 1 – Screen by one month of age
  - 3 – Diagnose by three months of age
  - 6 – Fit with amplification and enrolled in early intervention by six months of age
- Challenges:
  - Universal screening (100% of babies)
  - Loss to follow-up (after screening, diagnosis)
Why screen for hearing loss at birth?

• **Common**
  – Prevalence: 3 in 1000 babies

• **Hard to Predict:**
  – Healthy babies can have hearing loss – many infants with hearing loss have no other risk factors
  – 90% of infants born with hearing loss have normal hearing parents and no history of childhood hearing loss in their family (recessive)
  – Difficult to detect without a test until milestones are missed (too late)
  – Responding to a parent’s voice does not rule out hearing loss!

• **Critical Period:**
  – Neural plasticity, access to sound, growing the brain
  – Significantly better language, social, vocabulary, speech, literacy skills compared to children diagnosed and receiving intervention after 6 months of age

Which babies are at risk of hearing loss?

• 5 days or more in the NICU
• Blood transfusion to treat severe jaundice
• Exposure to certain infections before birth
• Has head, face or ears shaped or formed in a different way than usual
• Has a neurological disorder associated with hearing loss
• Meningitis
• Received injury to the head that required hospital stay
• Chemotherapy
• Family history of hearing loss
• Parent concern about child’s hearing
TED TALK

https://www.youtube.com/watch?v=5yK4Z7n5Nsl

History of Early Hearing Detection in Oregon

Watch the Oregon Trail to EHDI here:

http://prezi.com/yjkxfyuj3wq6/?utm_campaign=share&utm_medium=copy&rc=ex0share

(you may need to highlight the link above, right click, and select “open hyperlink” to view)
Where in the World is Oregon EHDI?

What defines the program?

<table>
<thead>
<tr>
<th>Oregon Law OAR 333-020-0125...0165</th>
<th>Centers for Disease Control and Prevention</th>
<th>Health Resources and Services Administration</th>
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</thead>
<tbody>
<tr>
<td>Authorizes Oregon Health Authority to develop, adopt rules, implement registry, tracking and recall system</td>
<td>Works with states and territories to meet EHDI 1-3-6 goals</td>
<td>Focus: reducing loss to follow-up and using quality improvement techniques</td>
</tr>
<tr>
<td>NO $$$</td>
<td>Intent: all newborns enrolled in registry, infants who refer and those diagnosed enrolled in tracking and recall system</td>
<td>Focus: the development and maintenance of information system and evaluation</td>
</tr>
<tr>
<td>All screening and diagnostic providers...shall report child-specific information to the Authority for the purposes of...needed services</td>
<td><strong>40% of budget ($163K)</strong></td>
<td><strong>60% of budget ($250K)</strong></td>
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<td>1.2 FTE</td>
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Oregon Legislative Mandate to Screen

All Oregon hospitals/birthing centers

– With more than 200 births per year:
  • each newborn child shall receive a newborn hearing screening test within one month of the date of birth, and attempt to conduct the test prior to the discharge

– With fewer than 200 live births per year:
  • shall provide the parent or guardian of a newborn child with information concerning the importance of newborn hearing screening tests.

National

– 43 of the 50 states have legislation related to EHDI

Our CDC and HRSA Goals

CDC
1. Complete planned development and maintenance of the EHDI-IS.
2. Collect individualized data on every occurrence birth through the three components of the EHDI process.
3. Analyze collected EHDI data and use the findings to guide the work of the program and engage stakeholders.
4. Strengthen EHDI-IS by using and disseminating evaluation results.
5. Advance the EHDI system to include data collection, monitoring and analysis of language and communication outcomes.

HRSA
1. Oregon’s newborn hearing screening rate will improve from 96% to 97%.
2. Oregon’s diagnostic follow-up rate will improve from 53% to 68% for infants who refer on newborn hearing screening.
3. Oregon’s early intervention enrollment rate will increase from 69% to 75% for infants diagnosed with hearing loss.
Successes and Challenges in Screening

• Screening rate for US: 97.2% (2013)

• Screening rate for Oregon: 97.3% (2014)
  – Mandated hospital (93.6% of Ore. births): 99.4% screened
  – Non-mandated hospital (2.5% of Ore. births): 91.6% screened
  – Home births (2.5% of Ore. births): 41.1% screened
  – Birth Centers (1.5% of Ore. births): 69.1% screened

Loss to Follow-up

• Despite good screening rates, families may struggle to make it to the next step.

• Primary reasons for loss to follow-up:
  – Counseling: what we tell families is very important!
  – Denial, post-partum emotion/depression/stress
  – Travel ability/expense/distance
  – Availability of facilities (shortage of pediatric audiologists, rural areas)
  – Communication barrier/cultural differences
  – Lack of primary health care/birth provider support
  – No insurance/financial difficulties
  – Child care for other children

• 76% of referred babies receive follow-up (2014)
After Diagnosis of Hearing Loss

- Infants are referred to
  - Guide By Your Side
  - Early Intervention
  - ENT for hearing aid clearance, medical evaluation of ear
  - Public Health Nurse
  - Return audiology appointments
  - Other specialists:
    - Ophthalmology
    - Genetics
    - Cardiac/Nephrology

Goals of Hearing Technologies

- Maximize infant’s access to:
  - speech sounds and cues
  - environmental auditory cues
  - auditory language
- Improve psychosocial outcomes
  - Family relationships
  - Peer relationships
- Increase academic opportunity
- Improve academic outcomes

Babies can be fit with hearing aids as soon as they are diagnosed!!
**Advisory Committee Members’ Role**

Come to meetings!

Participate –
join actively in the meetings; be a member

Represent –
yourself * your profession * your organization(s)

Carry –
information back to your networks and communities

Share –
information from your networks and communities

Assess –
opportunities to contribute and improve the system

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**What to do next?**

- Learn more about EHDI
- Host a meeting
- Complete your EHDI self/system assessment
- Connect the dots in your work, your office, your field
- Offer training and resources
- Educate your colleagues, clients and staff
Oregon EHDI Contacts

Main/General

- 1-888-917-HEAR (4327)
- Oregon.EHDI@state.or.us
- http://healthoregon.org/ehdi

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<thead>
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Additional Resources:

- National Center on Hearing Assessment and Management (NCHAM):
  – infanthearing.org
- NCHAM Newborn Hearing Screening Training Curriculum:
  – infanthearing.org/nhstc/index.html
- TEDx Talk on EHDI:
  – http://www.youtube.com/watch?v=bfN1RPVuzl0
- Oregon EHDI:
  – healthoregon.org/ehdi
- CDC – Hearing Loss:
  – cdc.gov/ncbddd/hearingloss/index.html