Early Hearing Detection and Intervention (EHDI): A Sound Beginning for Wisconsin’s Babies

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Learning Objectives
- Understand importance of early hearing detection and intervention
- Review Wisconsin Sound Beginnings Program and WE-TRAC
- Understand roles of primary care provider (PCP) /Medical Home and Early Hearing Detection and Intervention (EHDI) providers in promoting early detection and follow up
- Know about resources for families

Wisconsin Sound Beginnings
- Funded by federal Maternal Child Health Bureau and Centers for Disease Control (CDC)
- Promotes meeting Joint Committee on Infant Hearing (JCIH) goals of 1-3-6
- Focus on prevention of loss to follow-up in the EHDI system

Joint Committee on Infant Hearing
www.jcih.org
- Screen 100% of babies by 1 mo. of age – “Universal Newborn Hearing Screening”
- Babies who did not pass screening to diagnostic services by no later 3 mos.
- Identified babies linked to intervention services by 6 mos.

Early Identification of Hearing Loss is Important Because . . .
- Hearing loss is most frequent birth defect
- 1-3 babies per 1,000 born with significant hearing loss
- About 200 babies each year in WI

Vocabulary Size

Expressive Language Scores

<table>
<thead>
<tr>
<th>Language Age in Months</th>
<th>Identification Before 6 Months</th>
<th>Identification After 6 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-18 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19-24 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-30 months</td>
<td></td>
<td></td>
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<tr>
<td>31-36 months</td>
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</tr>
</tbody>
</table>

*Chronological Age in Months*

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What is WE-TRAC?

- Web-based system
- Mechanism for tracking & reporting of individual, hospital, and statewide aggregate newborn hearing screening data
- Allows electronic referrals
- Acts as safety net assuring timely and appropriate coordination of care throughout EHDI continuum

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Why is a data collection and tracking system necessary?

- Ensure every baby is screened
- Ensure every baby who does not pass screening gets timely and appropriate diagnostic and intervention services
- Support local providers' Quality Improvement efforts
- Monitor Wisconsin's progress toward meeting the JCIH 1-3-6 goals

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Wisconsin Hearing Screening Data

<table>
<thead>
<tr>
<th>Year</th>
<th>Births</th>
<th>Screened (%)</th>
<th>Missed (%)</th>
<th>Did Not Pass Screening (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>71,523</td>
<td>69,784 (97.6)</td>
<td>1,739 (2.4)</td>
<td>1086 (1.56%)</td>
</tr>
<tr>
<td>2008</td>
<td>70,871</td>
<td>69,487 (98.0)</td>
<td>1,384 (2.0)</td>
<td>719 (1.03%)</td>
</tr>
<tr>
<td>2009*** Preliminary</td>
<td>69,643</td>
<td>68,194 (97.9)</td>
<td>1,449 (2.1)</td>
<td>783 (1.15%)</td>
</tr>
</tbody>
</table>

*Includes children that were born out of hospital and international adoptions. This number is not used in any other category calculations (LTFU, Moved, Non Resident, Deceased, or Refused, With Normal Hearing, With Hearing Loss, or CHL with Confirmed Referral to EI) **Calculated from births screened for that year ***WE-TRAC data obtained 3/30/10

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Wisconsin Screening Data: Did Not Pass Screen

<table>
<thead>
<tr>
<th>Year</th>
<th>Did Not Pass Screening</th>
<th>Total LTFU/LTD (%)</th>
<th>Moved, Non-Resident, Deceased, or Refused (%)</th>
<th>With Normal Hearing (%)</th>
<th>With Hearing Loss (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>1086</td>
<td>680 (62.6)</td>
<td>125 (11.5)</td>
<td>185 (17.0)</td>
<td>96 (8.84)</td>
</tr>
<tr>
<td>2008</td>
<td>719</td>
<td>240 (33.4)</td>
<td>126 (17.5)</td>
<td>261 (36.0)</td>
<td>92 (12.8)</td>
</tr>
<tr>
<td>2009*** Preliminary</td>
<td>783</td>
<td>296 (37.8)</td>
<td>80 (10.2)</td>
<td>329 (42.0)</td>
<td>65 (8.3)</td>
</tr>
</tbody>
</table>

**WE-TRAC data obtained 3/30/10

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Not Screened

- 2007
  - NICU 290
  - No hearing program 443
  - Equipment failure 81

- 2008
  - NICU 51
  - No hearing program 397
  - Equipment failure 10

- 2009 (Preliminary)
  - NICU 179
  - No hearing program 348
  - Equipment failure 27

**WE-TRAC data obtained 3/30/10

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Not Screened by Region - 2009

<table>
<thead>
<tr>
<th>Region</th>
<th>Not Screened</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Southern</td>
<td>123</td>
<td>8.49%</td>
</tr>
<tr>
<td>Southeastern</td>
<td>199</td>
<td>13.73%</td>
</tr>
<tr>
<td>Western</td>
<td>101</td>
<td>6.97%</td>
</tr>
<tr>
<td>Northern</td>
<td>49</td>
<td>3.38%</td>
</tr>
<tr>
<td>Northwestern</td>
<td>85</td>
<td>5.87%</td>
</tr>
<tr>
<td>Home Birth</td>
<td>799</td>
<td>55.14%</td>
</tr>
<tr>
<td>Unknown</td>
<td>93</td>
<td>6.42%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1449</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

***WE-TRAC data obtained 3/30/10

Hearing Loss with Confirmed Referral to Early Intervention

<table>
<thead>
<tr>
<th>Year</th>
<th>With Hearing Loss</th>
<th>CHL with Confirmed Referral to EI (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>96</td>
<td>41 (42.7)</td>
</tr>
<tr>
<td>2008</td>
<td>92</td>
<td>39 (42.4)</td>
</tr>
<tr>
<td>2009***</td>
<td>Preliminary</td>
<td>65</td>
</tr>
</tbody>
</table>

***WE-TRAC data obtained 3/30/10

Role of the PCP/Medical Home

Screening
- All hearing screening results sent to you by screening hospital
- Hospital calls or faxes results of all DO NOT PASS screens – a “critical value”
- Hospital schedules follow-up appointment prior to discharge and offers referral to Guide-by-Your-Side Follow-Through Program
- Hearing screening results recorded and known by PCP/Medical Home and family at first newborn visit

Ongoing monitoring and identification:
- Provide ongoing developmental surveillance and screening per American Academy of Pediatrics policy statement
- Monitor those at risk according to 2007 Joint Committee on Infant Hearing guidelines

Coordination of care and planned encounters
- Confirm diagnostic audiology appointment at first visit
- Complete EHDI Care Map with family, planning and coordinating expected care and referrals
- Streamline authorizations to eliminate delay to specialty providers such as ENT and genetics
Role of the PCP/Medical Home

Care coordination continued
- Obtain a consent for release of information at first contact
- Refer to Birth to 3 within 48 hours of suspected diagnosis
- Offer and provide referral to:
  - Guide-By-Your-Side
  - Regional Center
  - Or other parent support groups

Resource Information Available

WI First Step
1-800-642-STEP (7837)
www.infoandreferralcenter.org

Role of Audiologist

- Remind families of their appointments one day in advance
- Provide families with instructions for a successful evaluation
- Prioritize newborn diagnostic exams
- Create expedited slots and schedule two appointments at a time

Role of Audiologist

- Coordinate care with family and PCP/Medical Home
- Verify PCP/Medical Home
- Provide clear communication about next steps to family and Medical Home
- Make referral to Birth to 3 within 48 hours of diagnosis
- Refer to Guide-By-Your-Side and copy of Baby and Hearing Loss notebook

Role of Birth to 3

- Obtain consent for release of information at first contact
- Provide regular communication to the PCP/Medical Home
- Develop IFSPs that address child’s communication needs and families priorities
- Confirm hearing status of every child in Birth to 3
- Monitor all areas of development

Role of Family

- Know the results of the hearing screening
- Partner in their child’s care
- Share what is needed and what they know
- Have a copy of their child’s care map
- Be prepared for visits
Guide-By-Your-Side (GBYS) Program

- Offers timely and direct parent/peer support
- Families can receive support at:
  - time of screening
  - confirmation of hearing loss
  - early intervention and
  - transition to early childhood placement
- A Program of WI Families for Hands and Voices, WI Department of Public Instruction, WI Educational Services Program-Deaf Hard of Hearing (WESP-DHH) Outreach, and WI Sound Beginnings
- Confidential and free

Guide-By-Your-Side (GBYS) Program

Parent Guides:

- Are parents of children with various degrees and levels of hearing loss, auditory neuropathy, combined vision and hearing loss, and deaf with additional disabilities
- Live all over the state of Wisconsin
- Have been trained to share unbiased information
- Share information about the unique needs of children with hearing loss, including insights on navigating the systems from a parent perspective

GBYS Contact Information

GBYS Follow Through Coordinator
- Helping reduce loss to follow up
  Connie Stevens, MA
  Connie.Stevens@dhs.wisconsin.gov
  608-266-0917

GBYS Program Coordinator
- Helping families after confirmation of hearing loss
  Laurie Nelson
  Laurie.Nelson@dpi.wi.gov
  608-822-3796
  888-656-8556 toll free

Resources for Families

Prenatal / At time of Screening
At time of diagnosis
At time of diagnosis

More Information on Early Hearing Detection and Intervention

www.infanthearing.org
National Center on Hearing Assessment and Management at Utah State University
www.babyhearing.org
Boys Town National Research Hospital
Wisconsin Sound Beginnings – Wisconsin Department of Health Services

Ask a Question

Viewing online?
- Click on the chat icon above
- Question emailed to Training Team
- Questions answered by expert on topic
- Response within 2-3 weeks
Acknowledgements

- Wisconsin Sound Beginnings Program, with funding support from Centers for Disease Control and federal Maternal Child Health Bureau
- Wisconsin Medical Home Webcast Series
- Wisconsin CYSHCN Program
- Waisman Center