

## 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

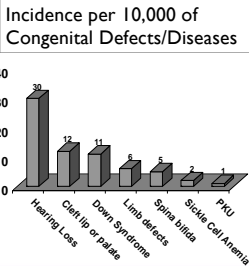
[www.jcih.org](http://www.jcih.org)

- 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.



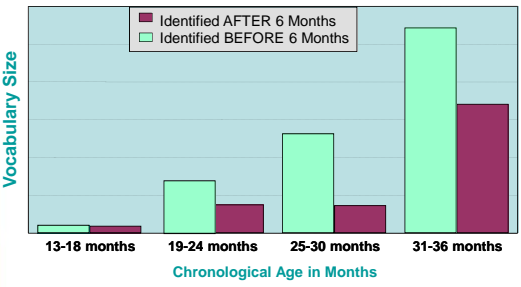
## Early Identification of Hearing Loss is Important Because . . .

- 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

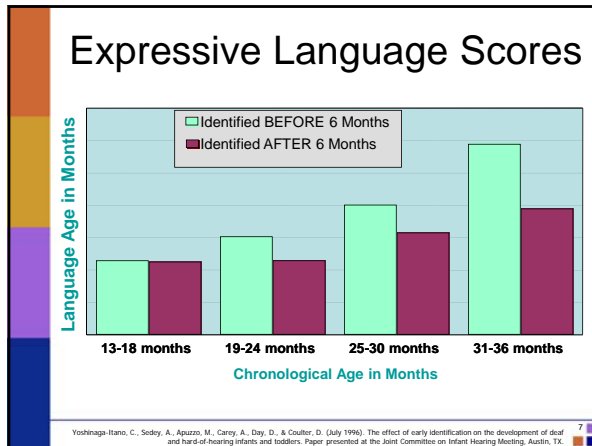


Defect/Disease	Incidence per 10,000
Hearing Loss	30
Cleft lip or palate	12
Down Syndrome	11
Limb defects	8
Spina bifida	7
Sickle Cell Anemia	2
PKU	1

## Vocabulary Size



Chronological Age in Months	Identified AFTER 6 Months	Identified BEFORE 6 Months
13-18 months	~5	~10
19-24 months	~10	~20
25-30 months	~15	~35
31-36 months	~30	~50



### 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

### 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

### Wisconsin Hearing Screening Data

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

\*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 Refuse, 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

### Wisconsin Screening Data: Did Not Pass Screen

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

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

- ### Not Screened
- |   |  |
|---|--|
| 2007 <ul style="list-style-type: none"> <li>• NICU 290</li> <li>• No hearing program 443</li> <li>• Equipment failure 81</li> </ul>               | 2008 <ul style="list-style-type: none"> <li>• NICU 51</li> <li>• No hearing program 397</li> <li>• Equipment failure 10</li> </ul> |
| 2009 (Preliminary) <ul style="list-style-type: none"> <li>• NICU 179</li> <li>• No hearing program 348</li> <li>• Equipment failure 27</li> </ul> |  |
- \*\*\*WE-TRAC data obtained 3/30/10

### Not Screened by Region - 2009

Region	Not Screened	Percent
Southern	123	8.49%
Southeastern	199	13.73%
Western	101	6.97%
Northern	49	3.38%
Northeastern	85	5.87%
Home Birth	799	55.14%
Unknown (includes international adoptions)	93	6.42%
<b>Total</b>	<b>1449</b>	<b>100%</b>

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

### Hearing Loss with Confirmed Referral to Early Intervention

Year	With Hearing Loss	CHL with Confirmed Referral to EI (%)
2007	96	41 (42.7)
2008	92	39 (42.4)
2009*** Preliminary	65	52 (80.0)

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

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

- ### Role of the PCP/Medical Home
- Ongoing monitoring and identification:
- o Provide ongoing developmental surveillance and screening per American Academy of Pediatrics policy statement
  - o Monitor those at risk according to [2007 Joint Committee on Infant Hearing guidelines](#)

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

### WISCONSIN SOUND BEGINNINGS PROGRAM Early Hearing Detection and Intervention (EHDI) Care Map

Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Birth	Infant	Infant 3 months	Infant 6 months
<b>Hospital based Neonatal Hearing Screening (NHS)</b> Lab test: <input type="checkbox"/> Passed <input type="checkbox"/> Failed <input type="checkbox"/> Incomplete <input type="checkbox"/> Date: ____/____/____ Right ear: <input type="checkbox"/> Passed <input type="checkbox"/> Failed <input type="checkbox"/> Incomplete <input type="checkbox"/> Date: ____/____/____ <input type="checkbox"/> GDS's Follow Through Card signed & sent to Parent/Guide	<b>Outpatient Screening Results (OAE/ABR)</b> Lab test: <input type="checkbox"/> Passed <input type="checkbox"/> Failed <input type="checkbox"/> Incomplete <input type="checkbox"/> Date: ____/____/____ Right ear: <input type="checkbox"/> Passed <input type="checkbox"/> Failed <input type="checkbox"/> Incomplete <input type="checkbox"/> Date: ____/____/____ <input type="checkbox"/> GDS's Follow Through Card signed & sent to Parent/Guide	<input type="checkbox"/> Pediatric Diagnostic Audiology Evaluation <input type="checkbox"/> Degree and configuration of hearing loss confirmed <input type="checkbox"/> Documented child and family hearing history <input type="checkbox"/> Received copy of Confirmation of Hearing Loss form from Audiologist <input type="checkbox"/> Refer to Birth to 3 (OEA, Part C) / First Step: 1-800-640-7037 <input type="checkbox"/> Medical & Otolgic Evaluations to recommend treatment and provide resources for hearing and living <input type="checkbox"/> Pediatric Audiologic hearing and living and monitoring <input type="checkbox"/> Family involved "Hearing Loss: Transition for Families" <input type="checkbox"/> Family referred to Guide By Your Side: 1-800-640-6996	<input type="checkbox"/> Enrollment to Birth to 3 (OEA, Part C) (Transition to Part B at 3 years of age) <input type="checkbox"/> Ophthalmologic (annual) <input type="checkbox"/> Dental <input type="checkbox"/> Developmental pediatric, neurology, cardiology, and nephrology (as needed) <input type="checkbox"/> Ongoing Pediatric Audiologic Services

**Caring Care of All Infants™**

- Provide parents with information about hearing, speech, and language milestones
- Provide parents with information about a genetic cause to hearing loss
- Identify and appropriately treat middle ear disease
- Vision screening and referral as needed
- Ongoing developmental surveillance / referral
- Referrals to ophthalmology and genetics, as needed
- Risk indicators for late onset hearing loss

**Medical Home:** \_\_\_\_\_  
**Pediatric Audiologist:** \_\_\_\_\_  
**Birth to 3 Contact:** \_\_\_\_\_  
**Guide By Your Side Contact:** \_\_\_\_\_  
**Regional Center Contact:** \_\_\_\_\_  
**Other:** \_\_\_\_\_

10) In screening programs that do not provide Outpatient Screening, infants will be referred directly to the Infant Diagnostic Audiology Evaluation. Licensed, trained, and highly qualified hearing loss, vision, and language specialists will be referred directly to the Infant Diagnostic Audiology Evaluation.  
 11) Infants who fail the screening in one or both ears should be referred for further screening.  
 12) Includes infants whose parents refused initial or follow-up hearing screening.  
 Nov 2009

## 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

19

## Resource Information Available

### WI First Step

1-800-642-STEP (7837)

[www.infoandreferralcenter.org](http://www.infoandreferralcenter.org)



20

## 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

21

## 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

22

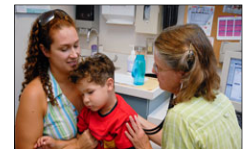
## Role of Birth to 3

- 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

23

## 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



24

## 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

25

## 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

26


## GBYS Contact Information

GBYS Follow Through Coordinator  
- Helping reduce loss to follow up  
Connie Stevens, MA  
[Connie.Stevens@dhs.wisconsin.gov](mailto: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](mailto:Laurie.Nelson@dpi.wi.gov)  
608-822-3756  
888-656-8556 toll free

27

## Resources for Families



Newborn Hearing Screening  
Prenatal / At time of Screening

A Guide for Families about Follow-up Medical Care  
At time of diagnosis

An Interactive Notebook for Families With a Young Child Who is Deaf or Hard of Hearing  
At time of diagnosis

28

## More Information on Early Hearing Detection and Intervention

[www.infanthearing.org](http://www.infanthearing.org)  
National Center on Hearing Assessment and Management at Utah State University

[www.babyhearing.org](http://www.babyhearing.org)  
Boys Town National Research Hospital


<http://dhs.wisconsin.gov/health/children/infanthearing/index.htm>  
Wisconsin Sound Beginnings – Wisconsin Department of Health Services

29

## 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



30

## Acknowledgements

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

31