

Newborn Hearing Screening: Success and Challenges



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March 2013

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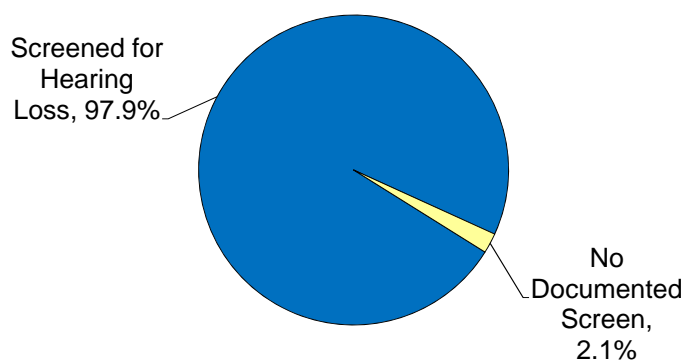
Hearing Screening in the U.S.

- No federal law requiring hearing screening & follow-up
- All states have an Early Hearing Detection and Intervention (EHDI) program
 - Most states have passed laws related to hearing screening but the requirements vary
- Ensuring infants are documented to receive recommended follow-up remains a key challenge

CDC EHDI Program

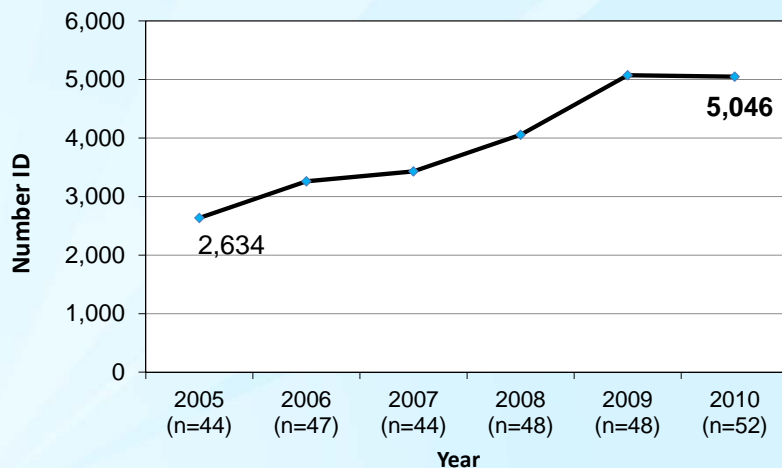
- Support the development & implementation of state-based EHDI Information Systems
 - Ensure infants receive recommended follow-up
 - Collect & report unduplicated, individual level data on all births
 - Promote integration w. other data systems
- Awarded 52 Cooperative Agreements
 - Provide technical assistance

Documented Hearing Screening Among Infants (U.S. 2010*)



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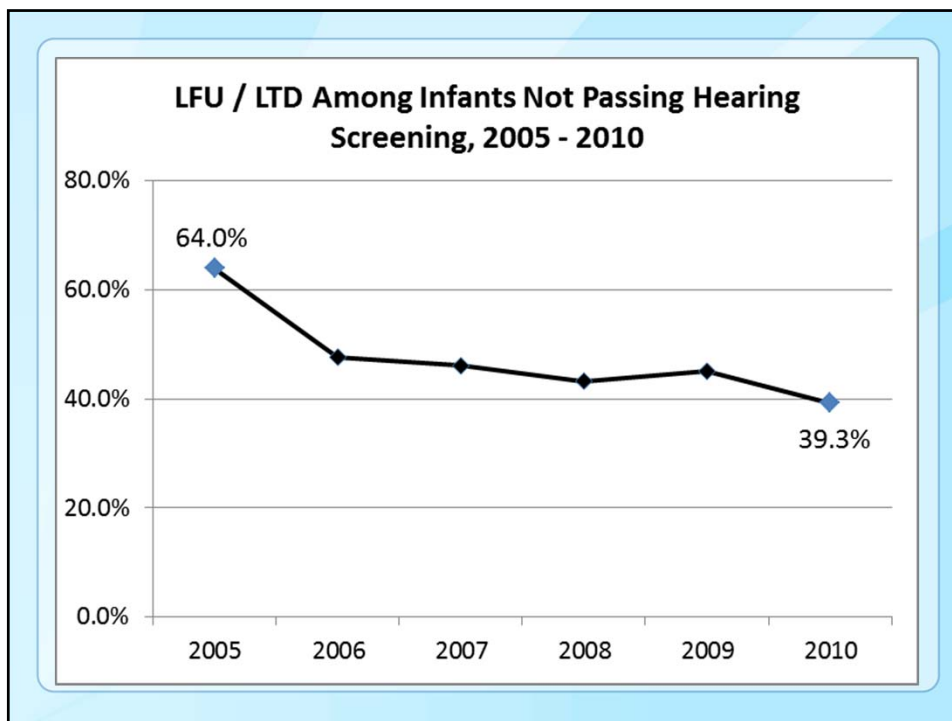
Infants Identified with Hearing Loss, 2005 – 2010 (*Total = 23,498*)



Challenges

- **Lost to follow-up (LFU)/Lost to documentation (LTD)**
 - LFU: Did not receive recommended services
 - LTD: Received services but the results are not reported
- **Without recommended follow-up the benefits of hearing screening can be severely diminished**
- **LFU/LTD occurs between:**
 - Screening – Rescreening
 - Screening – Diagnosis
 - Diagnosis – Intervention





Barriers: Screening

- Lack of standardized screening protocols
- High false positives rates
- Lack of protocols for presenting screening results
 - Families do not think follow-up is important
- Low patient volume can decrease quality of services

Barriers: Audiology

- Lack of audiologists who work with infants, especially in rural areas.
- Lack of communication and coordination between audiologists, medical home, families and EHDI program
 - Need for multiple diagnostic tests

Barriers: Family Issues

- Costs
- Lack of transportation
- Language (*Non-English speaking*)
- Transient nature of some families
- Confusion and/or lack of understanding



Barriers: Data Reporting

- Documentation
 - Lack of reporting requirements
 - Burden
 - Time
 - Duplicate data entry
 - Usability of systems
- Limited awareness about the importance of reporting and sharing data
 - Only report confirmed cases of hearing loss

CDC EHDI Survey: Background

- Hearing Screening and Follow-up Survey (HSFS)
 - Collects only aggregate data
 - Voluntary response
 - Data collected for years 2005 – 2011
- Developed in collaboration with state and national partners
 - Approved by the Office of Management and Budget
- Required to account for the status of all births

Survey: Goals & Uses

- Goal
 - Provide detailed and accurate data that reflects what is occurring across the U.S
- Uses
 - Provide data for states, the general public, and other interested persons
 - Help determine progress related to National EHDI Goals
 - Provide data for Healthy People (HP) 2020

Survey: Overview

- 3 Components
 - Part 1: Screening, Diagnostics, and Intervention
 - Part 2: Type & Severity of Hearing Losses
 - Part 3: Demographics
- Web-based survey
 - Includes error checks
 - Administered in January of each year

2010 Documented Screening (n = 54)

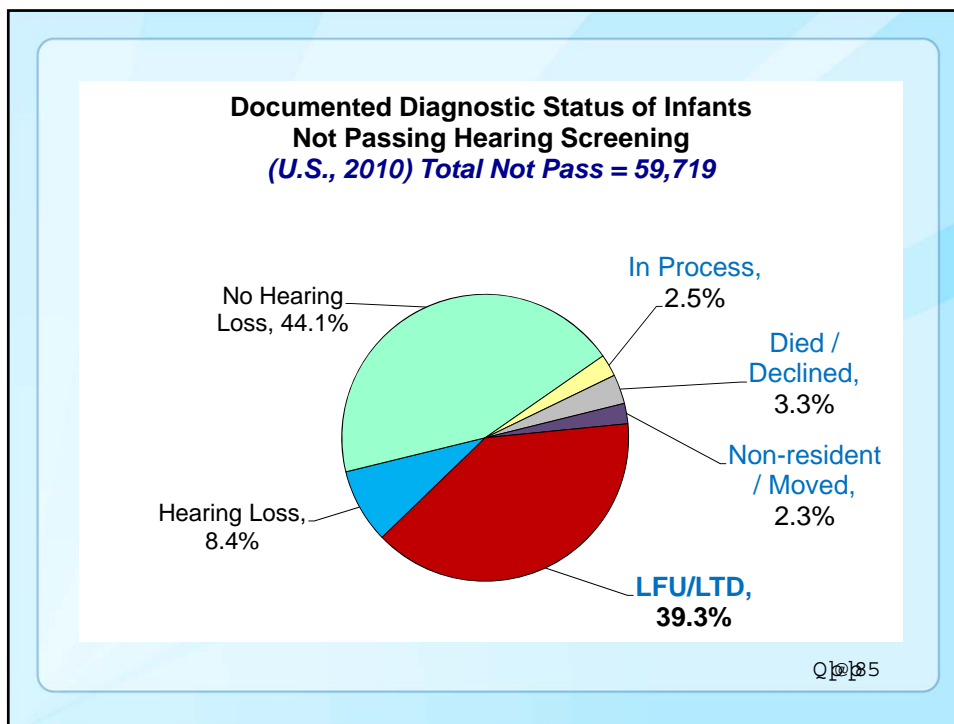
Occurrent Births	3,965,744
Percent Screened	97.9% (n = 3,881,048)
Percent Not Passing final / most recent screening	1.7% (n = 65,036)
○ Percent Not Passing Inpatient Screen & Not Receiving an Outpatient Screen*	13.7% (n = 8,935)

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2010 Documented Diagnosis (n= 52)

- 59,719 infants not passing final / most recent screen

Percent No Diagnosed Hearing Loss	44.1% (n = 26,324)
Percent Hearing Loss	8.7% (n = 5,046)
Prevalence of Hearing Loss	1.4 per 1,000 screened
Percent w. No Documented Diagnosis (of those Not Passing):	47.5% (n = 28,349)



2010 LFU / LTD for Diagnosis

- 59,719 infants not passing final / most recent screen

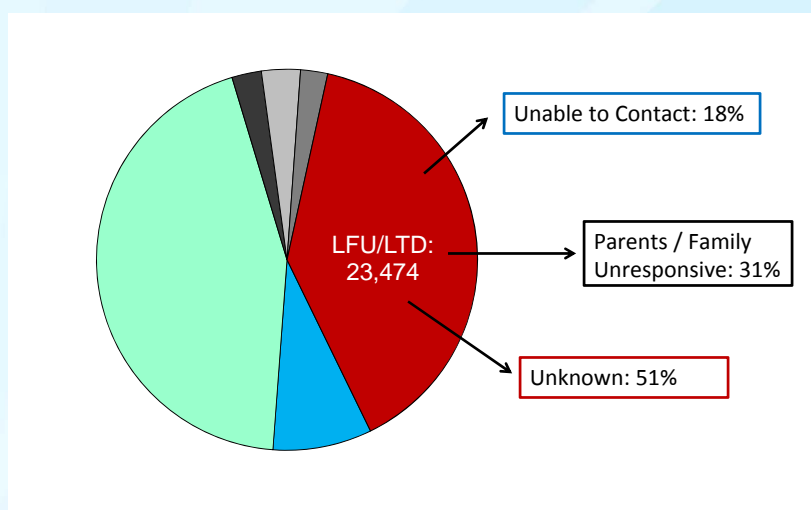
Percent w. No Documented Diagnosis	47.5%
○ Percent LFU / LTD for Diagnosis	39.3% (n = 23,474) (Range: 0 – 95%)

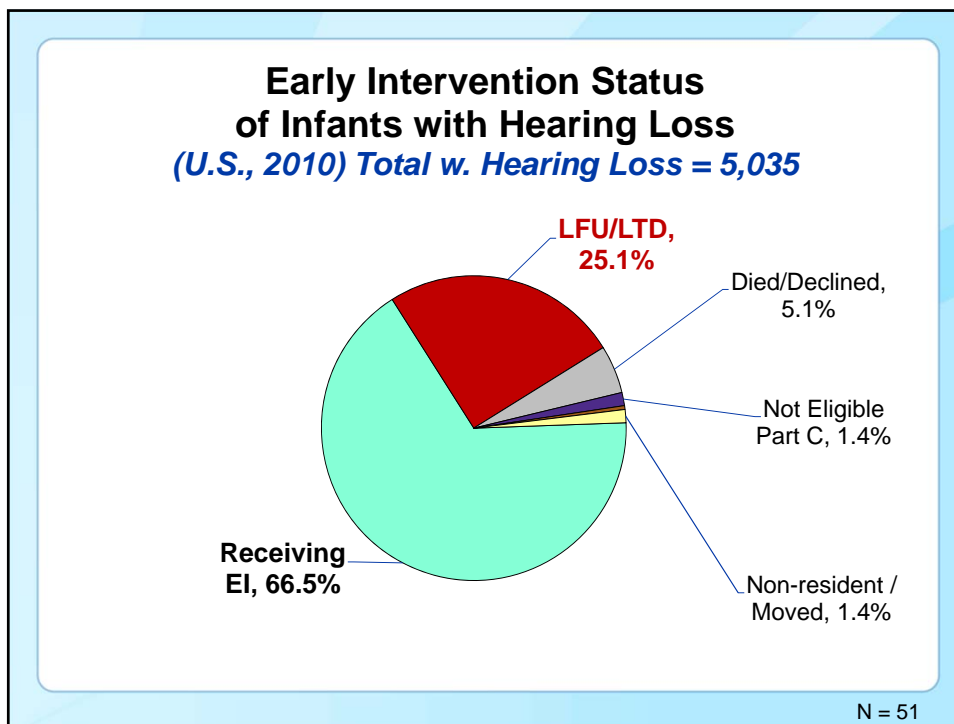
CDC Diagnostic LFU / LTD Formula

$$\frac{\# \text{ Unable to Contact} + \text{ Unresponsive} + \text{ Unknown}}{\# \text{ Total Not Pass Final Hearing Screening}} \times 100$$

$$\frac{4,259 + 7,251 + 11,964}{59,719} \times 100 = \mathbf{39.3\%}$$

LFU / LTD by Reason (2010)





Comparison of LFU / LTD for Diagnosis (2010)

LFU / LTD < 25%			LFU / LTD > 60%		
State	# LFU / LTD	% LFU / LTD	State	# LFU / LTD	% LFU / LTD
Massachusetts	35	2.9	Washington	716	63.4
Wyoming	5	13.9	Florida	969	64.8
Indiana	372	17.1	Utah	425	67.0
Rhode Island	17	18.3	Oregon	688	68.0
Kentucky	471	20.0	Alaska	176	74.3
Colorado	497	21.4	North Dakota	241	78.5
Oklahoma	581	21.8	Texas	4,395	79.8
Tennessee	799	22.6	Arkansas	468	81.7
Wisconsin	185	24.7	South Dakota	226	84.6
South Carolina	400	24.7	Montana	179	86.1

Variation in LFU / LTD


- **State Factors**
 - Births & geography (e.g., *rural areas*)
 - Variation in follow-up protocols
 - Legal requirements
- **Data Quality**
 - Incomplete reporting
 - Availability of individual vs. aggregate data
 - Limitations with data systems
 - Misunderstanding of CDC reporting guidelines

EHDI Data Online

www.cdc.gov/ncbddd/hearingloss/ehdi-data.html


- **Annual national & jurisdictional summaries**
 - By screening, diagnosis, and intervention
- **Type & Severity**
- **Demographic data**
- **Data comparisons & articles**

Thank you & Questions



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CHALLENGES TO MEDICAL HOME

Relatively low incidence of severe hearing loss	<ul style="list-style-type: none"> One of the most common congenital disorders
Lack of physician knowledge and education	<ul style="list-style-type: none"> Different terminology Misconceptions – success of UNHS
Getting newborn results	<ul style="list-style-type: none"> Difficulty with hospital Integrating with electronic medical records
Retesting in office	<ul style="list-style-type: none"> Reporting results
Family support	<ul style="list-style-type: none"> Less than 50% received needed support (H&V)
Working with EI	<ul style="list-style-type: none"> Working with community agencies 60-70% enrolled by 6 months (CDC)
Time constraints and financial constraints	

LEARNING FROM PARENT EXPERIENCES

Know when and where to refer

- Don't idly reassure
- Timely access to service is critical
- Excessive screening delays process
 - Need to define nature of problem when screening failed
- Connect parents to audiologist for hearing assessment
 - Many parents will not be persistent or know how to move forward on their own

Have written information / resources for parents

Know risk indicators for late-onset hearing loss and when to refer for hearing testing

Muñoz, K., DesGeorges, J., Forsman, I., Kennedy, S., & Nelson, L. (2010). Parent experiences with the infant hearing testing process. National EHDI Conference. Chicago, IL.

BEFORE ONE MONTH

Outpatient Rescreening

- Hospital
- Audiologist
- Retesting in Primary Care facility
- OAE
- ABR



LTF/D

- Communication with family, hospital, audiologist
- Office protocol?
- Office staff can help
- Don't pass – DO TEST!!

BEFORE 3 MONTHS

Pediatric audiological evaluation

Report to state EHDI

Early Intervention

Family support, education and information

Medical and ENT evaluation

Hearing aids



BEFORE 6 MONTHS

Early Intervention services

Etiology and associated problems

- ENT
- Eye
- Genetics
- Neurology, Developmental Pediatrics and others if needed

Audiological follow-up



WORKGROUP ON MEDICAL HOME AND LTF

- CDC
 - John Eichwald, MA, FAAA
 - Marcus Gaffney, MPH
- HRSA
 - Irene Forsman, RN, MS
- NCHAM
 - Diane Behl, M Ed
 - Karl White, PhD
- AAP STAFF
 - Faiza Khan, MPH
 - Corrie Pierce



MEDICAL HOME AND LTF/D AAP EHDI TASK FORCE

Obtain, document, and discuss all screening test results and risk factors by one month

- Whenever possible information should be received from the hospital rather than the parent
- Work with local birthing facilities to establish best method for obtaining test results

Coordinate care of a child that has a 'do not pass' screening result or for whom you cannot obtain the documented screening results

- Either screen, rescreen or arrange screen or rescreen by one month
- Medical Home takes lead in scheduling - Assist parents with rescreen appointment



MEDICAL HOME AND LTF/D AAP EHDI TASK FORCE

Confirm results with state EHDI program within 48 hours	<ul style="list-style-type: none"> • Need to learn state reporting program
IF 'do not pass' the second screen, refer to audiologist that has experience with infants and ensure follow-up appointment is scheduled	<ul style="list-style-type: none"> • Confirm appointments and notify state EHDI program • Refer to CDC EHDI Directory – EHDI PALS
Ensure family is referred to local EI program	<ul style="list-style-type: none"> • Medical home should get parent/family to release medical information/records to PCP so they can obtain the results

MEDICAL HOME AND LTF/D AAP EHDI TASK FORCE

Dedicated staff person in the practice	<ul style="list-style-type: none"> • Obtain all screening results • Coordinate the education/support of families • Relationship with State EHDI program
Provide education and support to families	<ul style="list-style-type: none"> • Hearing, speech, and language milestones • Discuss and explain all test results, next steps, and importance of follow-up • Confirm with family that follow-up appointments have been made and kept • Help to arrange transportation and social service support
Culturally competent and health literate appropriate information	<ul style="list-style-type: none"> • Hands and Voices, Guide-By-Your-Side, NCHAM, etc. • Educational options

RESCREENING IN THE MEDICAL HOME – AAP EHDI TASK FORCE

Report results

Oto-acoustic
Emission (OAE)

- NICU babies
- Failed ABR
- Auditory neuropathy/dyssynchrony
- Need to know screening protocol!

Technical
recommendations



RESCREENING IN THE MEDICAL HOME

Calibration

Technique

3 times
maximum
attempts

NCHAM support
– ECHO
initiative

- www.infanthearing.org/earlychildhood/healthcare.html



CAN THE MEDICAL HOME REDUCE LTF/D?

It's tough to make predictions, especially about the future.

~Yogi Berra

