

# *Evaluation of EHDI Programs*

*National EHDI Coordinators Meeting*



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# *Why do we need to evaluate our EHDI programs?*

- Meet the needs of families we serve
- Measure and improve performance
- Evidence based approach/strategies
- Evaluate success or challenges
- Understand disparities
- Educate and promote
- Allocate resources
- Motivate stakeholders
- Contribute to literature

## *Healthy People 2010*

- Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months.
- Potential data sources: State-based Early Hearing Detection and Intervention (EHDI) Program Network, CDC and/or specific State data.

## *National EHDI Goals and Objectives*

- Goal 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.
- Goal 2. All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.
- Goal 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention).

## *EHDI Goals Continued*

- Goal 4. All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.
- Goal 5. All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics.
- Goal 6. Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up.

## *JCIH Year 2007 Position Statement: Principles and Guidelines for EHDI Programs*

- Outlines detailed information that can be used in developing evaluation strategies and action plans
- Recommends periodic evaluation of EHDI Programs including:
  - Improving quality
  - Efficiency
  - Usefulness

*HRSA, Maternal and Child Health  
Bureau Block Grant Performance  
Measure*

- # 12. Percentage of newborns who have been screened for hearing before hospital discharge.

# *Government Performance and Results Act (GPRA) – MCHB*

1, 3, 6 goals:

- # of infants with a positive screen who are lost to follow-up
- # of infants with confirmed or suspected hearing loss referred to an ongoing source of comprehensive health care (medical home)
- # of children with nonsyndromic hearing loss who have developmentally appropriate language and communication skills at school entry



## *National EHDI Program Objectives and Performance Indicators*

- Provides a framework to measure standardized outcomes nationally
- Informative and motivating for stakeholders
- Practical tool for developing state goals and objectives
- Valuable for grant writing

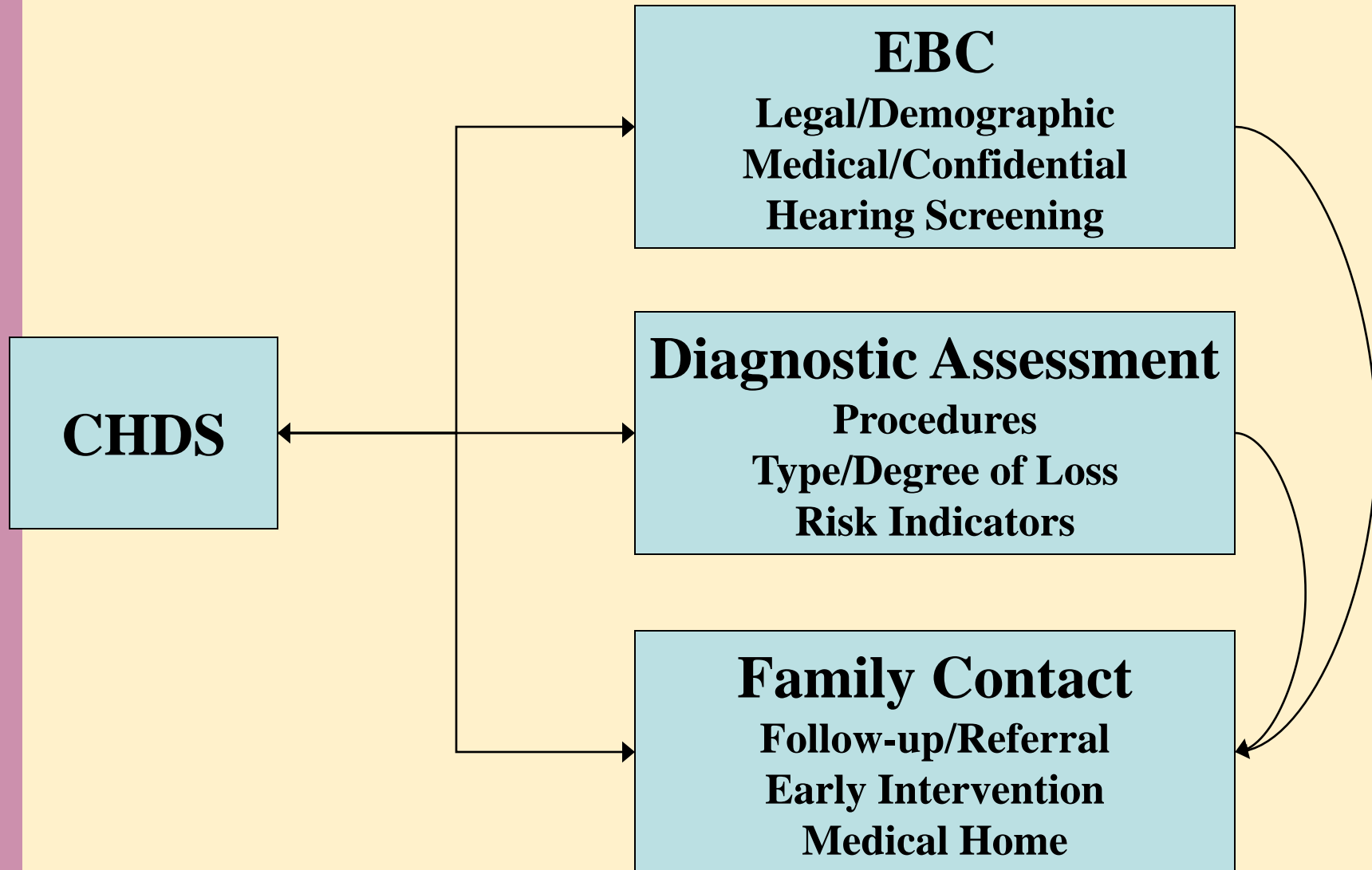
# *A Comprehensive Approach to EHDI Evaluation*

- Identify staff skilled in high level data software
- Analyze and clean data regularly
- Start cleaning 2010 annual data now
  - Provides more time to follow-up with facilities and families
- Understand your target population and who becomes lost to follow-up
- Identify racial and ethnic, health, geographic and other disparities
- Meet with families, stakeholders and consumers through focus groups to be certain program strategies meet the needs of the population served

# *Logic Models, Diagrams, Systems Documentation*

- Childhood Hearing Data System
- Data Flow Diagrams
- Logic Models
  - Data Driven
  - Programmatic

# *MA EHDI Data*



## *MA Quality Improvement*

- Hospital report cards (annual)
- Quarterly data reports to birth facilities and diagnostic centers
  - Special emphasis on transferred infants
  - HL degree and type not determined
- Verification of screening results for infants listed as passed and later identified with HL

# Annual Hospital Report Card Template



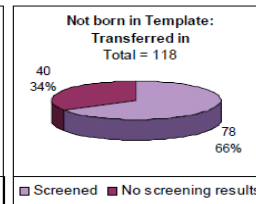
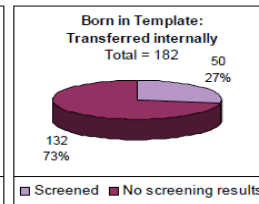
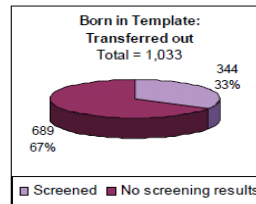
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## Template Hospital Newborn Hearing Screen Summary

**PRELIMINARY DATA**  
 Birth Year: 2009

	Template Hospital		Overall Massachusetts	
Total Births				
Total Screened <sup>1</sup>	Passed		Passed	
	Failed		Failed	
Total Not Screened	Transferred <sup>2</sup>		Transferred <sup>2</sup>	
	Missed/unknown		Missed/unknown	



**FINAL DATA**  
 Birth Year: 2008

	Template Hospital		Overall Massachusetts	
Total Births				
Total Screened <sup>1</sup>	Passed		Passed	
	Failed		Failed	
Total Not Screened	Transferred <sup>2</sup>		Transferred <sup>2</sup>	
	Missed/unknown		Missed/unknown	

Birth Years: 2008, 2007, 2006

Birth Year	Population	Total births	Total passed (%)	Total missed (%)	Total failed (%)	Total with hearing loss (%)	Total in Early Intervention (%)
2008	Overall MA						
	Template						
2007	Overall MA						
	Template						
2006	Overall MA						
	Template						

1. Final screening results from birth hospital and secondary hospitals  
 2. Includes internal transfers and transfers to a secondary facility



# Diagnostic Center Reports

## 2008 data

### Facility Name:

This report is a summary list of infants who were born in 2008 and failed their newborn hearing screen (NHS).

They fall into one of the following 2 categories for your facility:

- 1) These infants are lost to follow-up: they had a scheduled appointment at your facility, but we did not receive any data from you.
- 2) These infants were evaluated at your facility, but we are awaiting a final confirmatory diagnosis.

Total MA births =

Total failed NHS =

1) Lost to follow-up total for the state =

**Lost to follow-up total for your facility =**

2) Diagnosis pending total for the state ~

**Diagnosis pending total for your facility ~**

Child's DOB

Child's Name

Child's DOB

Child's Name

- Infants without a confirmatory diagnosis are listed on this report. They fall into one of the two most common categories:
  - Lost to follow-up/documentation
  - Diagnosis pending



# *Examples of the data we evaluate in MA*

## SCREENING

- Missed screens (0.5%) - predominantly homebirths and transferred infants

## DIAGNOSTICS

- Lost to follow-up (4.2%) – analyzed by geography
- # diagnosed with hearing loss (>200)
- Non-consents (2.2%)
- Hearing loss by laterality of referral – 1 in 4 bilateral referrals were diagnosed with HL
- Late onset HL - 25 out of 29 had risk indicator(s)
- Laterality of HL by type and degree of loss
- Risk indicators (# and percentage)
- Median age at diagnosis (1.10 months in 2008)

## EARLY INTERVENTION

- # lost to follow-up (19.8%)

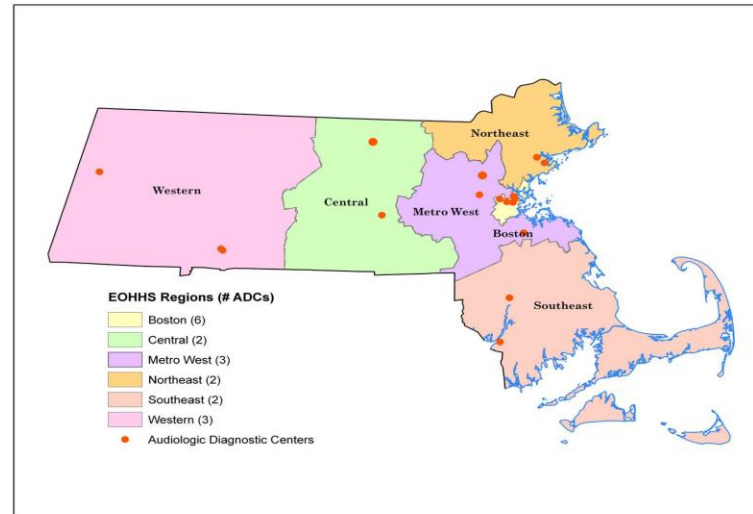
## *Age in Months of Diagnosis of HL*

<b>Year of Birth</b>	<b>Number Diagnosed with Hearing Loss</b>	<b>Median Age at Diagnosis (in months)</b>	<b>Average Age at Diagnosis (in months)</b>
2004	225	1.15	2.32
2005	207	1.20	2.04
2006	226	1.25	2.35
2007	212	1.13	1.71
2008	202	1.10	1.90

## *Risk Factor Statistics for Infants with HL* (2008)

Risk Factor	NHS refer		Confirmed Hearing Loss	
	N = 1405	%	N = 202	%
<b>Infants with risk factors</b>	468	33.3	140	69.3
<b>Premature (&lt;37 weeks)</b>	250	17.8	58	28.7
<b>LBW</b>	194	13.8	53	26.2
<b>Family history of HL</b>	92	6.6	28	13.9
<b>Assisted vent</b>	79	5.6	31	15.3
<b>Down's Syndrome</b>	25	1.8	12	5.9
<b>Cleft Palate</b>	16	1.1	10	5.0
<b>Herpes</b>	13	0.9	2	1.0
<b>Atresia</b>	13	0.9	13	6.4
<b>Positive toxicology</b>	9	0.6	3	1.5
<b>Ototoxic medications</b>	7	0.5	3	1.5
<b>Hyperbilirubinemia</b>	6	0.4	3	1.5
<b>HL Syndromes</b>	6	0.4	4	2.0
<b>Speech/language delay</b>	5	0.4	3	1.5
<b>Other craniofacial</b>	5	0.4	3	1.5
<b>Cleft Lip</b>	5	0.4	3	1.5
<b>CHARGE association</b>	**	**	**	**
<b>Pulmonary HT</b>	3	0.2	3	1.5
<b>CMV</b>	2	0.1	2	1.0
<b>Head trauma</b>	1	0.1	0	0.0
<b>Other risk factors</b>	58	4.1	30	14.9

# Lost to Follow-up by Residential Region (2008)



EOHHS Region	Total referrals	LTFU (%)
<b>Overall</b>	1405	59 (4.2)
<b>Boston</b>	263	12 (4.6)
<b>Central</b>	114	4 (3.5)
<b>Metro West</b>	321	9 (2.8)
<b>Northeast</b>	327	10 (3.1)
<b>Southeast</b>	299	16 (5.4)
<b>Western</b>	63	7 (11.1)

## *MA and National EHDI Evaluation Projects*

- NICHQ Learning Collaborative (4/08-3/09)
- MA Evaluating Loss to Follow-up (published Pediatrics 6/08)
- CDC Family Satisfaction Project (published ASHA, 6/07)
- RTI, An evaluation of lost to follow-up in state EHDI programs (6/07)
- ASHA Lost to Follow-up Workgroup (09)
- MA Downs Syndrome Evaluation Project
- Pregnancy to Early Life Longitudinal Study (PELL)

# Research Questions in PELL

Linkage of UNHSP data to PELL, which provides data on maternal and child hospital discharges, Emergency Room visits, fetal deaths and observational stays.

- Down Syndrome Evaluation Project:
  - Characterize type and degree of hearing loss among children born with DS in MA
  - Identify disparities associated with timely hearing loss diagnoses or EI participation
- Evaluate UNHSP data quality and accuracy in comparison with PELL ICD-9 codes
- Evaluate disparities associated with use of health services when failing a newborn hearing screen
- Evaluate the timeliness of hearing loss diagnoses and access to hearing aids or cochlear implants as appropriate
- Explore maternal and infant perinatal medical risk factors associated with infant hearing loss.
- Explore medical and socio-economic risk factors associated with late onset hearing loss.



*Inform policies pertaining to screening, rescreening, timely diagnosis, and access to Early Intervention. Develop best practices guidelines for infants with demographic or complex medical risk factors.*

# *NICHQ Learning Collaborative*

Improve the health and well-being of children and youth with special health care needs

- Through small tests of change (PDSA), reduce the number of home birth and transferred infants that miss a hearing screen
- Partner with Beth Israel Deaconess Medical Center and Brigham and Women's Hospital

# *PDSA Example*

## *Objective*

Reduce the number of missed hearing screenings for babies discharged from the NICU

- Best method for tracking transferred infants since only birth hospital has access to EBC?
- True missed vs. lost to documentation
- What are the reasons for missing information?
- Who determines if babies being transferred were in need of screening?
- If babies were screened, were they screened again upon transfer?



## *Plan and Do*

- Beth Israel and Brigham and Women's Hospitals identified transfer facilities that received infants transferred out of their NICUs
- UNHSP provided contacts for the screening program directors for those transfer facilities
- Contacted 4 hospitals accepting at least 5 infants transferred from the NICU, for whom UNHSP was missing screening information
- Confirmed if hearing screening was actually performed
- UNHSP received a fax of results for all babies that had a hearing screen

## *Study and Act*

- Analyzed number of true missed screens compared to number lost to documentation of screening results
- Determined why infant(s) missed their screen or why screening information was not transmitted
- Make policy or procedure changes accordingly

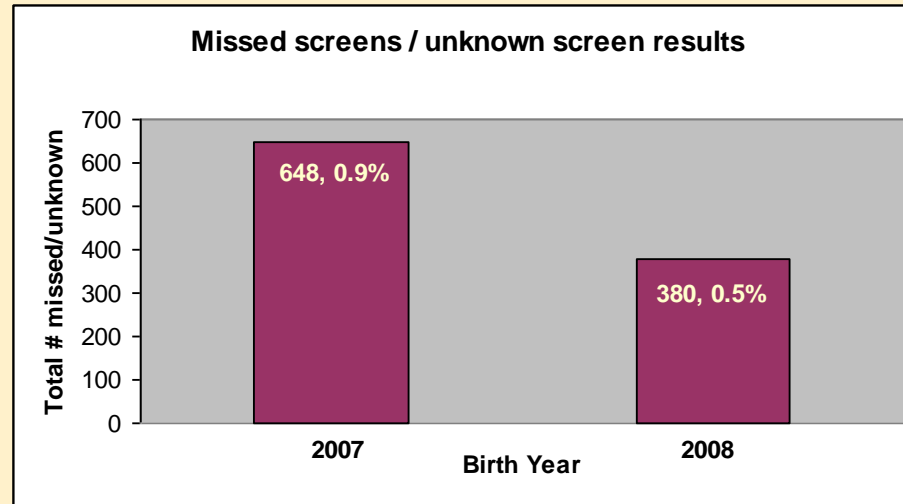
## *Lessons learned*

- Most infants were screened, but data was never reported to UNHSP (lost to documentation)
- Interpretations varied for when a transferred newborn should be screened
- Many screening directors do not have access to census of babies transferred into their facility

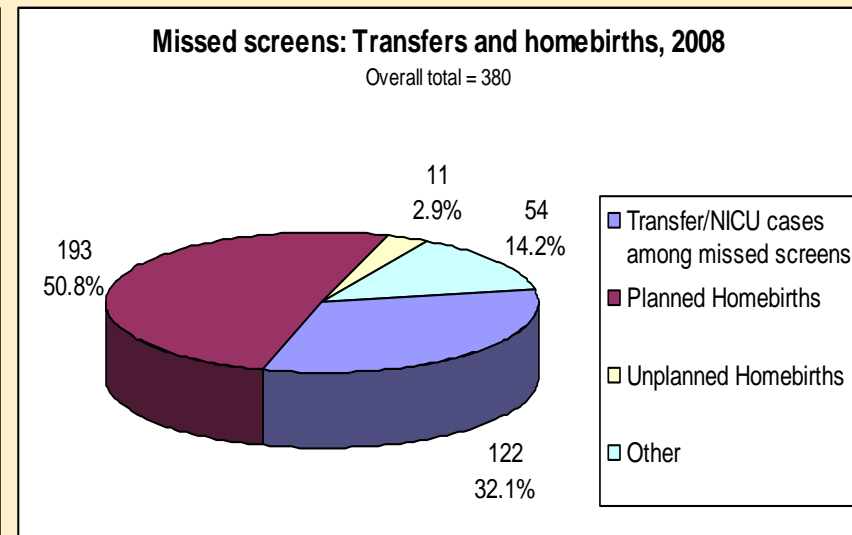
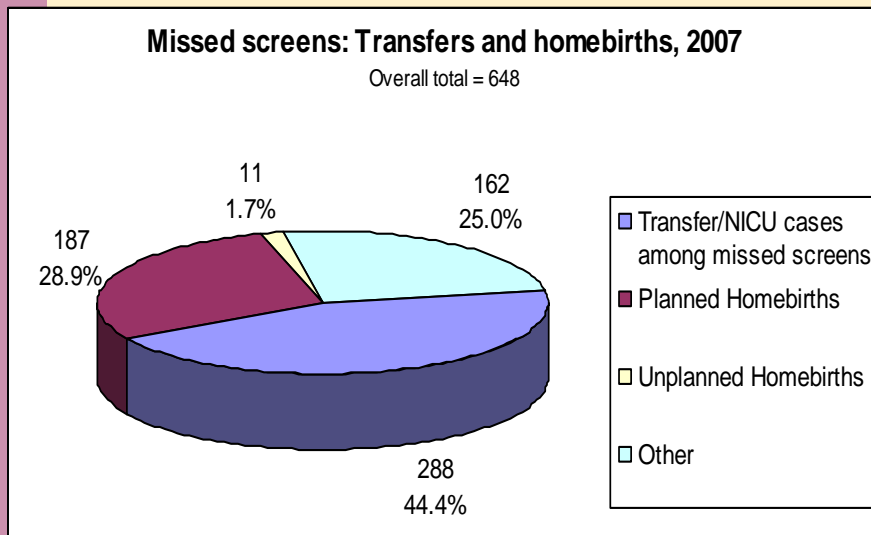
## *Next steps*

- Developed and disseminated new data transmittal form statewide
- In collaboration with the Advisory Committee, update birth facility guidelines to include “best practices” algorithm for screening transferred infants

# Missed screens / unknown screen results: 2008 vs. 2007



From 2007 to 2008, there was a 41.4% decrease in the number of infants who missed a screen or had unknown results.



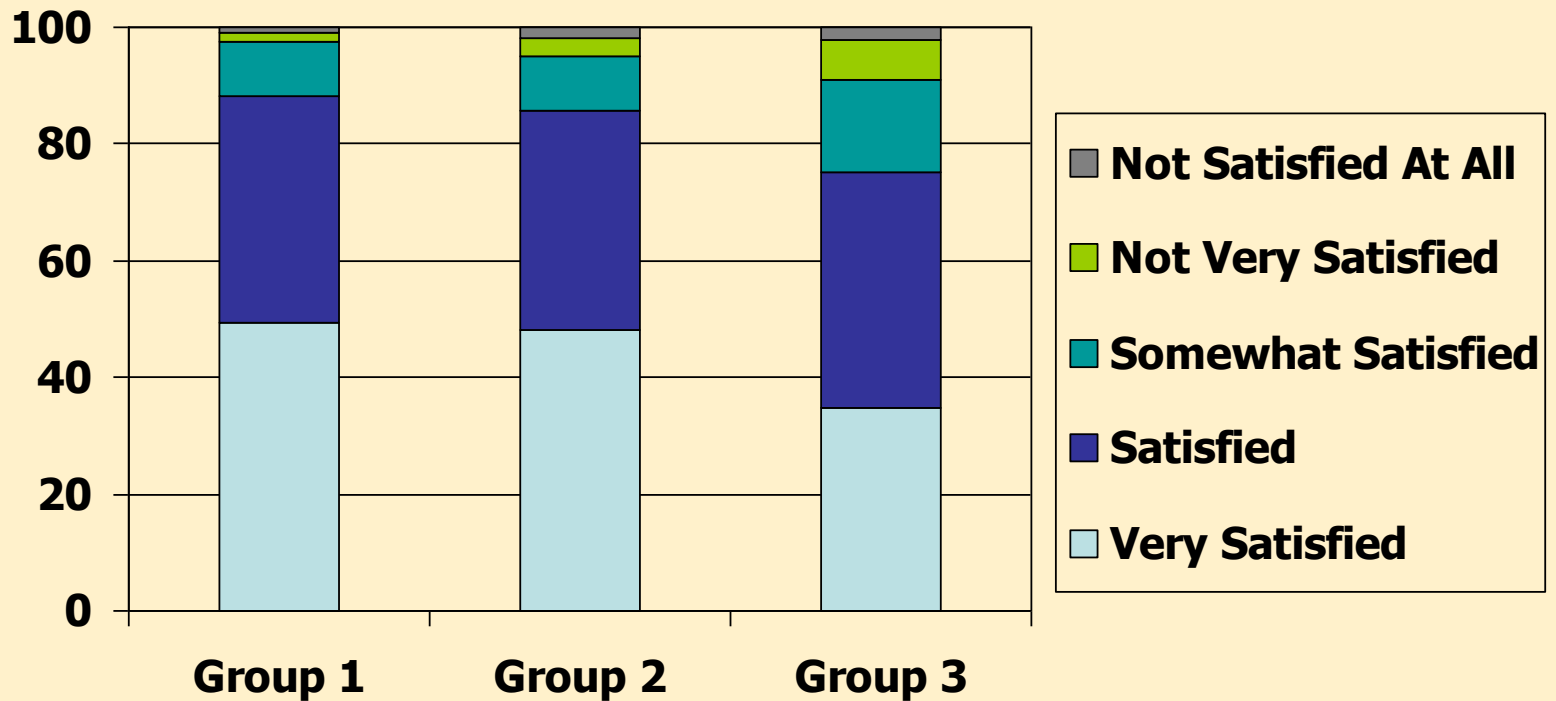
# *Family Satisfaction Study*

- To determine the levels of families' satisfaction and anxiety associated with the EHDI process
- To determine what factors affect families satisfaction levels with the EHDI process
- To assess whether or not a child's hearing status affects the levels of satisfaction

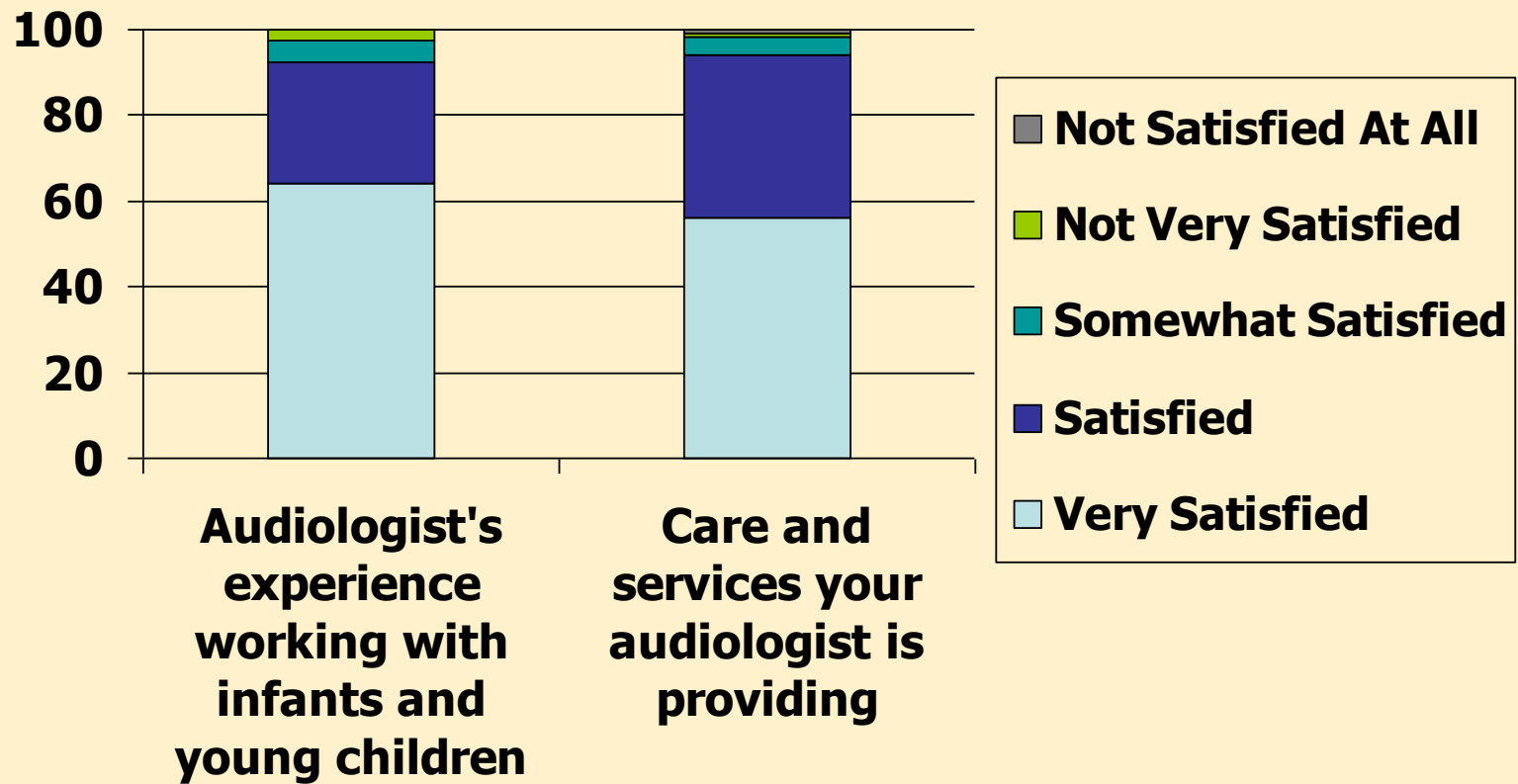
## Three study groups

1. Families whose newborn passed
2. Families whose infants refer on their initial screening but passed outpatient screen or diagnostic
3. Families whose infants are identified with permanent hearing loss

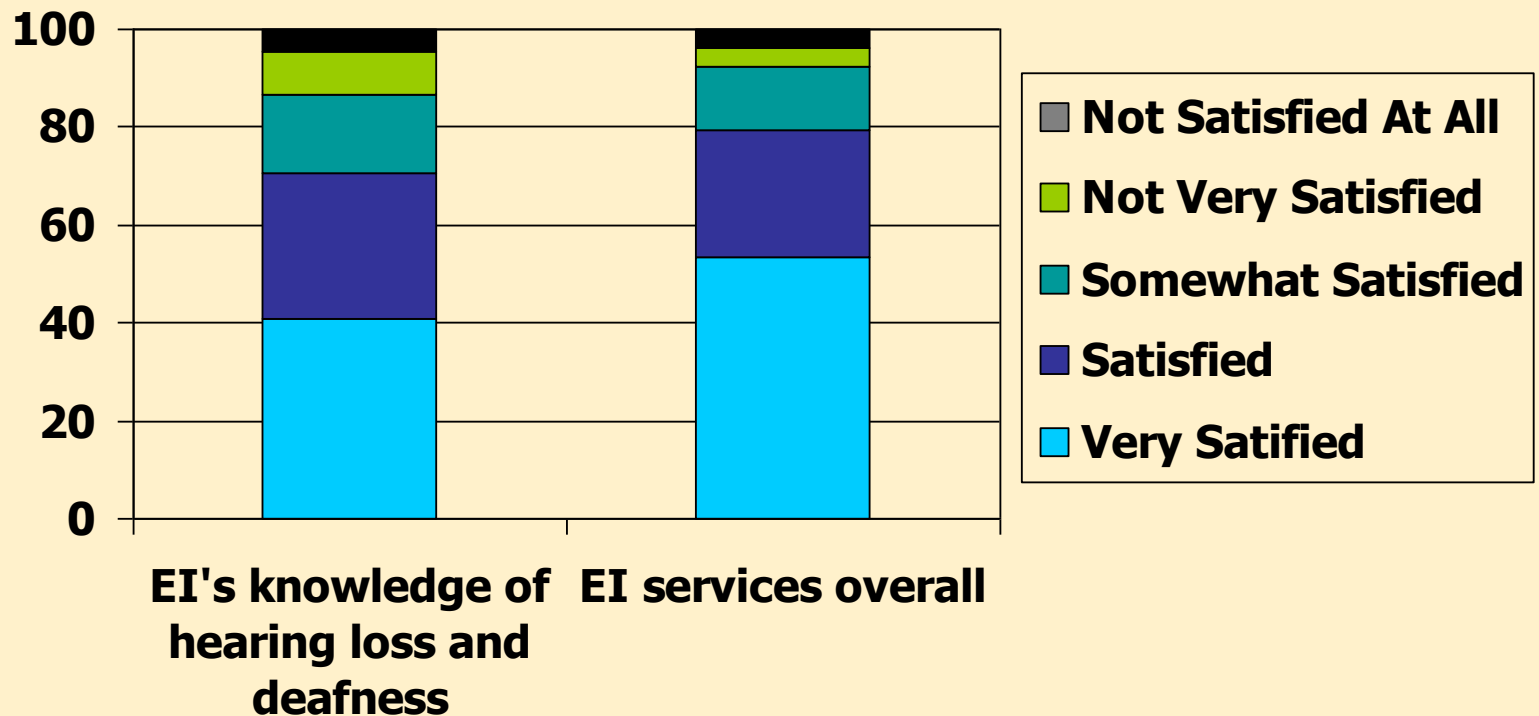
# *Satisfaction with Screening*



## *Satisfaction with Audiologist – Group 3*



## *Satisfaction with EI – Group 3*





*If you had another baby, would you want him or her to have his or her hearing screened?*

- Group 1 = 99%
- Group 2 = 99%
- Group 3 = 98%

## *Five Year Strategic Plan (2011-2016)*

- Hired an outside consultant
- Assessed gaps, opportunities, feasibility, potential impact
  - Broad strategies
  - Specific tactics
- Staff, families, stakeholders are included in the strategic planning vision process
  - Family meeting planned 3/11 (focus groups)
- Conducted best practices interviews with other states
- Developing vision, objectives and actions for newborn hearing screening for the next five years

*Mission: Providing strong leadership to create positive outcomes for children with hearing loss and their families*

## Vision and Strategies (Early Hypothesis)

- Awareness and education
- Family support
- Stakeholder Engagement
- Policy
- Surveillance and Evaluation
- Interventions
- Infrastructure

## *Five Year Evaluation Strategy*

- Maintenance of high quality data
- Timely analysis and dissemination of data
- Monitor emerging trends and disparities
- Studying Down syndrome diagnostic outcomes
- Interest in evaluating EVA data
- **Develop systems to analyze developmental outcomes**
- Identify data sources and gather data on later identified children with HL

# *Questions*

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