Early Hearing Detection and Intervention: The Role of the Medical Home

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### **Today's Topics**

- Connecticut's EHDI Program
- Engaging child health providers through academic detailing
- The EPIC presentation

### Connecticut's Early Hearing Detection & Intervention (EHDI) Program

### Ann Gionet CT Department of Public Health



### **Connecticut EHDI Program**

- Program Components:
  - Universal Newborn Hearing Screening oversight
  - Data collection, tracking and surveillance
  - Provider education
  - Parent education
  - Partnership building
    - Audiologists, Otolaryngologists, Primary Care Providers, Parents, Early Intervention Providers
  - Grants management (federal \$\$)



### **CT** Legislation

#### Connecticut General Statutes, Section 19a-59:

a) Not later than July 1, 2000, each institution as defined in section 19a-490 of the Connecticut General Statutes that provides childbirth services shall develop and implement a universal newborn hearing screening program as part of its standard of care and shall establish a mechanism for compliance review. The provisions of this subsection shall not apply to any infant whose responsible party objects to hearing screening as being in conflict with their religious tenets and practice.

 b) The Department of Public Health shall establish a plan to implement and operate a program of early identification of infant hearing impairment....



### **UNHS:** Connecticut's History

- 2000 Universal hearing screening of newborns was implemented in all 31 CT birth facilities
- 2002 CT birth hospitals began *electronically* reporting newborn screening results to DPH
- 2003 Standardized screening equipment statewide



Otoacoustic emissions (OAE)



Automated Auditory Brainstem Response (AABR)

### CT Newborn Screening System Hospital Data Reporting: Mother and Baby Demographics

A Hospital Record					
<u>F</u> ile Forms <u>H</u> elp					
Med. Rec.: 5097505 Acc.: 7103	33371 Mother's Name: Test				
Find/New Biographical Laboratory	Hearing Birth Defect Registry				
Birth Mother					
Name (Last) * (First) *	Address (Street, Apartment Number) *				
Test	address				
Telephone # * Date Of Bi	irth *				
() - //					
Baby					
N	Sex * Birth Sequence *				
Name (Last) * (First) Test	Male Single V				
	ht (Grams) * Race * Hispanic Origin Surrogate				
Birth Date * Birth Time * Weigh					
	(Weeks) * Hospital NICU Or SCN On Antibiotics BreastFeed				
Hartford	0 No 💌 🔍				
Primary Care Provider (PCP) after Discharge	e				
Name (Last) * (First)	Address (2 lines)				
Telephone # *					
<u>C</u> ommit Biographical Data					
* Indicates Required Field	Initiate transfer Accept Transfer <u>Save</u> E <u>x</u> it <u>H</u> elp				

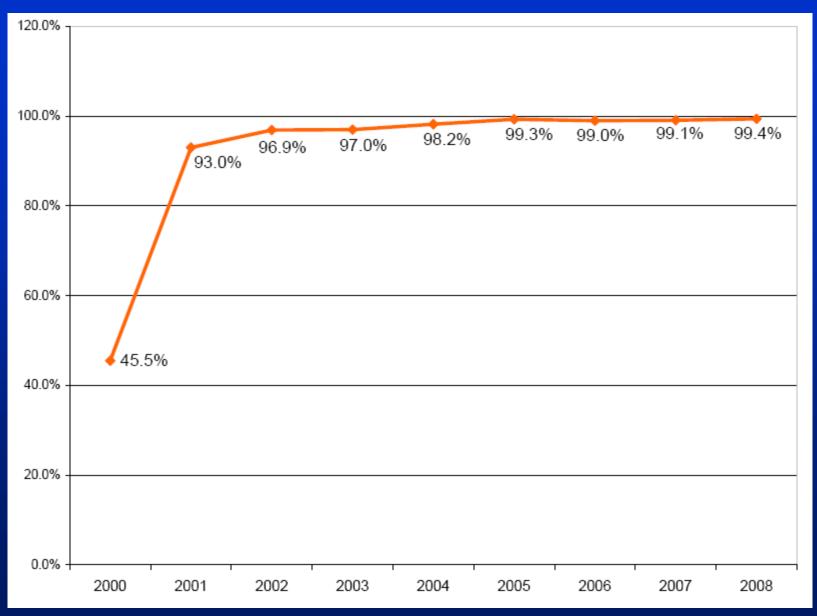
### CT Newborn Screening System Hospital Data Reporting: Hearing Screening Results

Hospital Record					
<u>File Forms Help</u>					
Med. Rec.: 5097505 Acc.: 71033371 Mother's Name: Test					
Find/New Biographical Laboratory Hearing Birth Defect Registry					
Parental Consent					
Parent Refused Screening If Yes, Date Of Refusal: //					
Screening 1					
Screener (last): * (first) * Date: * / /					
Method: None Right: * NOT TESTED Left: * NOT TESTED					
Screening 2					
Screener (last): [ (first) Date: / /					
Method: None Right: NOT TESTED Left: NOT TESTED					
Notifications and Risk Factors					
Audiologist Referral PCP Notification Parental Notification Risk Factors					
No 💌 None 💌 None 💌 Risk Factors					
Audiologist Referral					
Name (Last) First Address (2 Lines)					
Telephone # Appointment Date					
<u>C</u> ommit Hearing Data					
* Indicates Required Field Initiate transfer Accept Transfer <u>Save</u> Exit <u>H</u> elp					

### Hospital Newborn Hearing Screening Protocol

- Well Baby Nursery
  - 1<sup>st</sup> screen: OAE or ABR
  - 2<sup>nd</sup> screen: ABR (before discharge)
- NICU infants, admitted for >5 days
  - Auditory brainstem response (ABR) screening
  - Assists in identifying neural hearing loss (auditory neuropathy / dyssynchrony)
    *Joint Committee on Infant Hearing*, 2007

### **CT Annual Newborn Hearing Screening Rates**



### Annual Percentage of Babies Screened who Did Not Pass Newborn Hearing Screening

Year	Connecticut		
2005	0.85%		
2006	0.92%		
2007	0.83%		
2008	1.15%		
2009	1.59%		

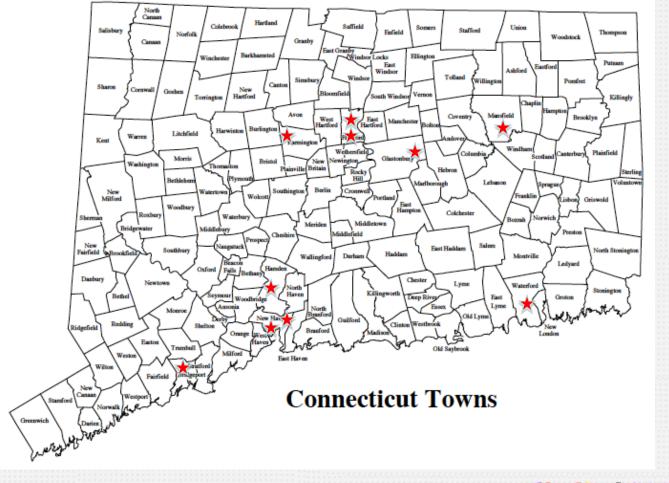


### What Happens After the Screening?

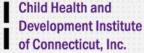
- Refer to designated diagnostic audiological testing centers in CT
  - Must be an experienced "pediatric" audiologist
  - Be completed by 3 months of age
  - Include <u>both</u> ears
  - Includes a battery of tests, should include an ABR assessment
  - Sedation done in a medical facility with appropriate monitoring available, if needed



### **Infant Diagnostic Testing Locations**



Children's Fund of Connecticut



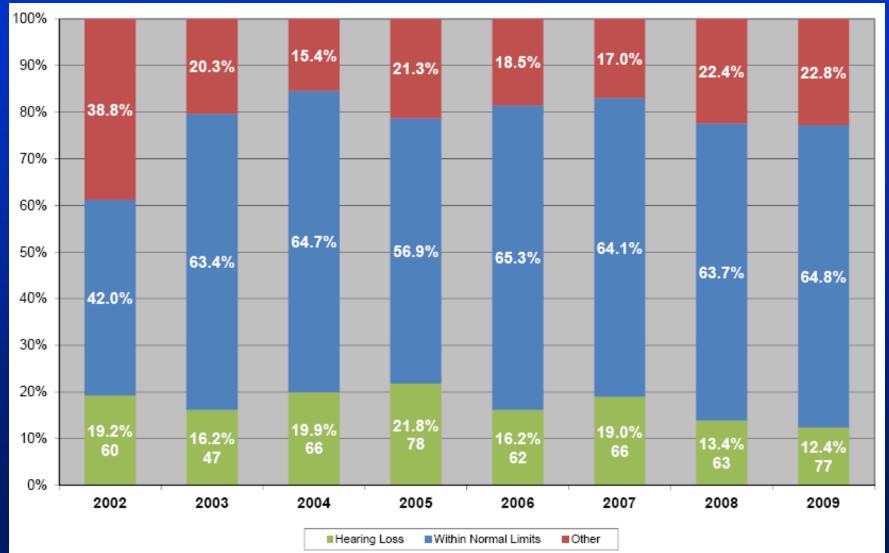
### **CT EHDI Database**

Audiological Data Reporting / Early Intervention Data

- Audiological follow-up results
  - Date of evaluation
  - Type of evaluation (rescreen or dx tests conducted)
  - Status
    - In Progress
    - Hearing Within Normal Limits
    - Hearing Loss (ear specific results type and degree of hearing loss)
  - Audiology Center and Audiologist
- Early Intervention referral & enrollment data
  - Date and age at referral and enrollment
  - EI (Birth to Three) Program selected



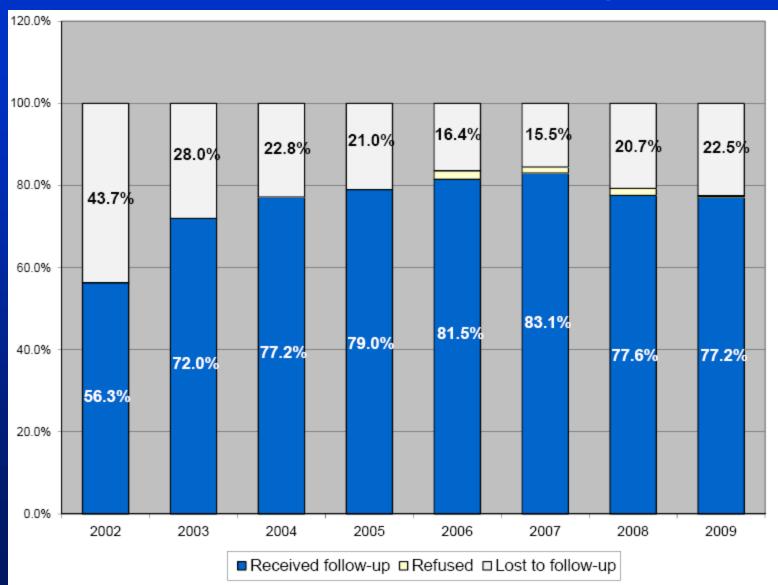
### CT: Annual Percentage of Babies Not Passing NBHS Identified with Hearing Loss vs. Hearing WNL



### Lost to Follow-Up (LTF) / Lost to Documentation (LTD)

- Any newborn who does <u>not</u> pass the hospital screen and does <u>not</u> have documented audiologic follow-up within 12 mos from DOB
- Babies who do <u>not</u> receive follow-up testing and <u>cannot</u> be found are considered "Lost to Followup."
  - Extensive tracking by DPH EHDI staff before calling child "Lost"

### CT: Annual %-age of Babies Receiving Follow-up After Failure to Pass Newborn Hearing Screening



### Early Intervention Services in CT

- After diagnosis the baby is referred to Birth to Three
  - Anyone can make the referral
    - Usually referred by the diagnosing audiologist
  - Referrals made via the Child Development InfoLine (CDI), (800) 505-7000

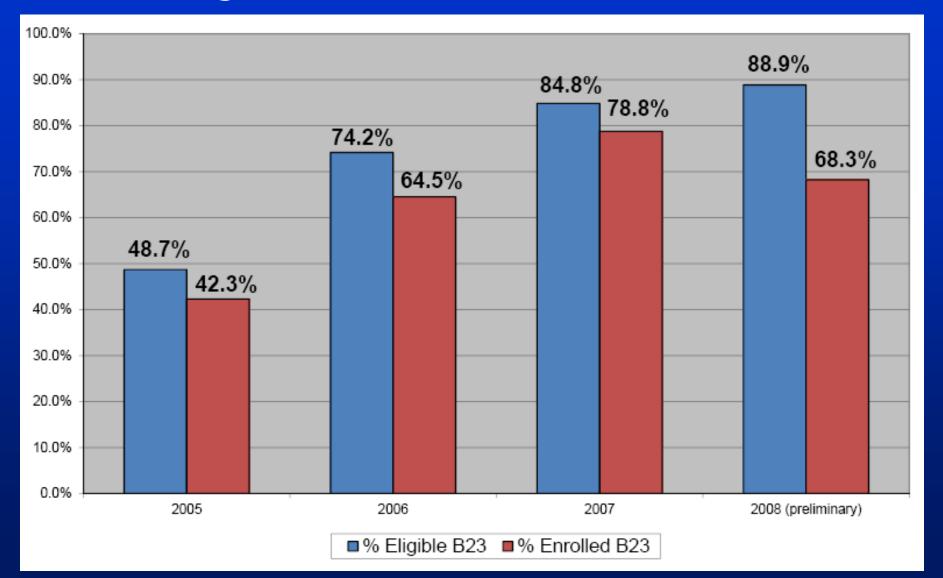
### Birth to Three Services

- General and specialty programs
- Conduct developmental assessments
- Provide speech/language therapy, audiology services, amplification, mapping, family support & education, etc.
- Services in home-like environment
- Individualized Family Service Plan (IFSP) for each child
- Cost of Services: Sliding fee scale based on family size & income

### CT Birth to Three

- Automatic eligibility:
  - A permanent hearing loss of 25dB or greater in either ear OR persistent middle ear effusion that is documented for 6 mos or more with a hearing loss of 30 dB or greater (as of July 1, 2007)
- Birth to Three Specialty Programs that specialize in working with children who are deaf or hearing impaired
  - American School for the Deaf
  - CREC/Soundbridge
  - New England Center for Hearing & Rehabilitation (NECHEAR)

### CT: Annual Percentage of Babies with Hearing Loss Eligible and Enrolled in Birth to Three



### Educating Practices in the Community (EPIC)

Lisa Honigfeld, Ph.D. Vice President for Health Initiatives Child Health and Development Institute

## How are medical homes doing in serving children with hearing loss?

## 2002 survey of pediatricians (n=107) from one state

- 59% agreed that they were the medical home for children with hearing loss
- 43% felt well informed about the services available for children with hearing loss
- 45% felt well informed about paths of follow up
- 63% agreed that they should coordinate care, but only 41% reported that they do

Dorros C, Kurtzer-White E, Ahlgren M, Simon P, and Vohr B. **Medical Home for Children With Hearing Loss: Physician Perspectives and Practices**. Pediatrics 2007; 120: 288-294

# How are medical homes doing (cont.)

- 2006 US national study (n=1,968)
- 82% believed that screening all newborns was very important
- 89% expressed confidence is discussing the screening process with parents
- However, when asked specific questions about follow up for newborns who refer from hospital screening, pediatricians did not show extensive knowledge about accepted protocols and practices

Moeller MP, White KR, and Shisler L. **Primary Care Physicians' Knowledge, Attitudes, and Practices Related to Newborn Hearing Screening**. Pediatrics 2008; 118: 1357-1370

### How to Improve Your Practice's Care for Children with Hearing Loss



## EPIC uses academic detailing to the whole practice to change behavior

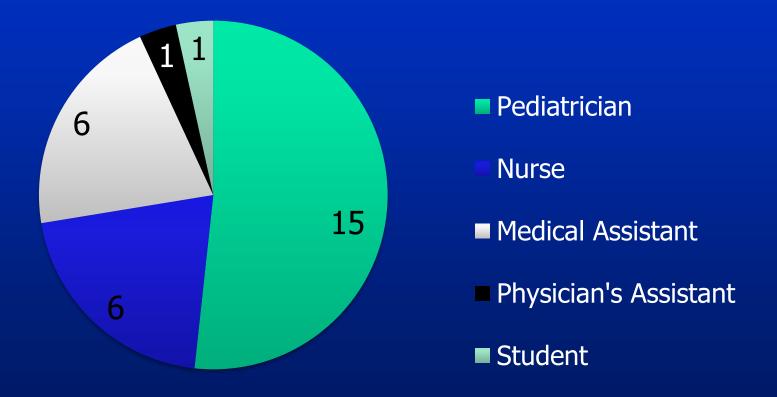
### Elements of academic detailing:

- 1. Recognition of baseline knowledge and motivation for and barriers to change
- 2. Clear educational objectives and desired behavioral change
- 3. Reference to authoritative and unbiased information
- 4. Stimulating participation in educational interaction
- 5. Utilization of concise graphic material
- 6. Repetition of essential messages
- 7. Some follow up/positive reinforcement

### EPIC Presentations October 2010 to January 2011

-5 office presentations-31 evaluations collected

### **Role of Respondents in Office**



### Respondents' Intent to Use Information from Presentation

1/ Definitely Intend to Use	2	3		5/ Definitely Not Intend to Use
77%	16%	6%	0%	0%

### Respondents Reporting that Training was Useful

1/ Very Useful	2	3		5/ Not Useful
71%	23%	6%	0%	0%

### Aspects Respondents Reported as Valuable

	Checked (Yes)	Not Checked (No/No response)
Information	94%	6%
Convenience	68%	32%
Lunch	68%	32%
CME Credits	0%	100%

### **Respondents' Reported Barriers to Using Information**

	1/Not	2	3	4	5/ May
	а				be a
	Barrier				Barrier
Lack of Time	48%	24%	7%	14%	7%
Not enough					
information	54%	<b>29%</b>	7%	4%	7%
Information too					
difficult to use	64%	25%	7%	0%	4%

**Pediatric Hearing Loss: Early Detection and Ongoing** Monitoring By **Brenda Balch, MD** Child Health and Development Institute of CT, Inc.

### Today's Presentation

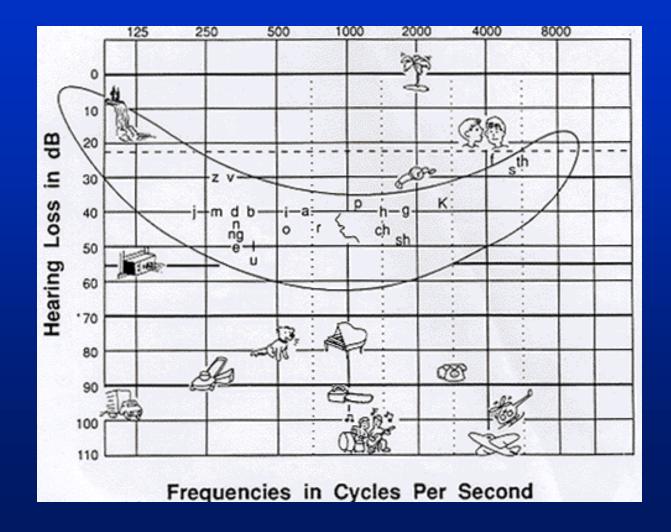
- Why hearing is important in young children
- Your role in ensuring that children who do not pass hospital newborn screening are connected to follow-up services
- Your role in ongoing hearing monitoring for all children

### Why Does Hearing Matter?

Hearing loss affects

- Language and speech development
- Social skills
- Learning and academic
- Achievement/success
- Safety

### Sounds on an Audiogram



### Newborns at Risk for Hearing Loss

- NICU admissions >48 hours
- Other signs/symptoms consistent with syndromes associated with hearing loss (e.g., neurofibromatosis, osteopetrosis, Usher's syndrome, Waardenburg syndrome, Alport syndrome)
- Craniofacial abnormalities
- Family history of childhood sensorineural hearing loss
- History of in utero infection (e.g., cytomegalovirus, rubella, syphilis, herpes, toxoplasmosis)

### Early Hearing Detection: "1-3-6"

All infants should be screened by <u>1 month of age</u>

Infants who fail screening should received formal audiology evaluation by <u>3 months of age</u>

Infants with hearing loss should start receiving related intervention by <u>6 months of age</u>

### The Medical Home's Role

- Communicate with specialists (audiologist, otolaryngologist, geneticist and other specialty providers deemed appropriate)
- Monitor development and address developmental/behavioral issues as they arise
- Provide support and educate families including connecting them with family support opportunities in the community

### After "1-3-6": Who is at Most Risk?

#### Infants and children with:

- Aforementioned issues
- History of hyperbilirubinemia requiring transfusion, pulmonary hypertension associated with mechanical ventilation, or use of ECMO
- Neurodegenerative disorders (e.g., Hunter syndrome, sensory motor neuropathies like Friedreich's ataxia and Charcot-Marie-Tooth syndrome)
- Ototoxic medication exposure (chemotherapy, aminoglycosides, or loop diuretics)
- Down syndrome

After "1-3-6": Who is at Most Risk

Infants and children with:

- Significant postnatal infection such as bacterial meningitis
- Recurrent/persistent otitis media
- Head trauma
- Previously detected mild/unilateral hearing loss
- Speech/language delay
- Caregiver concern about hearing, speech/language

### For ALL children, the medical home:

- Provides ongoing monitoring for children who pass hospital hearing screen but have risk factors for hearing loss
- Is on the look out for late onset or progressive hearing loss not detected through hospital newborn screening
- Performs developmental surveillance at every visit and formal screening at 9, 18, and 24(or 30 months) of age

### For ALL children, the medical home:

- Ensures that hearing is evaluated if parents express concern about speech/language or autism
- Subjectively assesses hearing at every visit and objectively tests at 4, 6, 8 and 10 years of age
- Connects children for whom there are concerns to appropriate evaluation and intervention services (1 800 505-7000)

### Review: Hearing Loss Monitoring in the Pediatric Medical Home

- Confirm results of newborn screening
- Pursue audiology evaluation if necessary
- Ensure connection to Birth to Three if necessary
- Conduct ongoing hearing surveillance
  - Identify subsequent hearing loss as soon as possible
    - Late onset
    - Progressive
    - Acquired
    - Connect children to appropriate diagnostic and intervention services

