Connecticut Department of Public Health

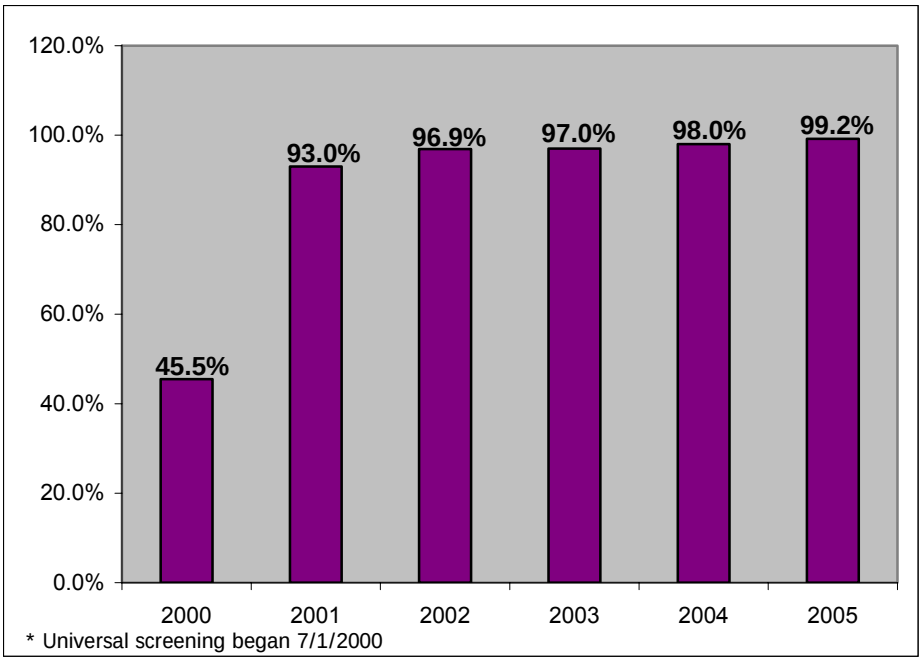
Early Hearing Detection and Intervention (EHDI) Program

2005 Annual Report

Mission Statement

The goal of universal newborn hearing screening is to provide early hearing detection and intervention in an effort to prevent speech, language and other delays and support children in reaching their maximum potential.

Connecticut Annual Hearing Screening Rates



History of Newborn Screening in Connecticut

1985– CT General Statute (C.G.S.) 19a-59 required a plan to identify "at risk" infants for hearing loss

1993- National Institute of Health Consensus Development Conference recommended that all newborns be screened for hearing loss before hospital discharge

1999- Joint Committee on Infant Hearing, American Academy of Audiology and American Academy of Pediatrics supported universal hearing screening of infants

1999– CT amended C.G.S. 19a-59

> *"Each institution, as defined in section 19a-490, that provides childbirth service shall, not later than July 1, 2000, include 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."*

2000- Universal hearing screening of newborns was implemented in all 31 birth facilities

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EHDI Program

Family Health Section
Public Health Initiatives Branch
Connecticut Department of Public Health

Voice 860 509-8057
TTY 860 509-7191

www.dph.state.ct.us/bch/EHDI.htm

Facts About Hearing Loss...

- Every day in the United States approximately 1 in 1,000 newborns (or 33 babies a day) is born profoundly deaf and another 2-3 per thousand are born with a partial hearing loss.
- Newborn hearing loss is twenty times more common than phenylketonuria (PKU) and is the number one birth defect in the U.S.
- Congenital hearing loss that is not detected within the first few months of life significantly delays speech and language development.
- Not all forms of hearing loss are expressed at birth and may be progressive or late onset.
- Infants identified with a hearing loss can be fit with amplification as young as 4 weeks of age.
- Only half of the 12,000 babies born in the U.S. annually with some form of hearing loss exhibit a risk factor.
- The first few months of life offer the critical "window of opportunity" for stimulating the auditory pathways to the hearing center of the brain, necessary to help children learn fundamental language, social, and cognitive skills.

2005 Connecticut EHDI Statistics

Total births in CT	42,142
Percent of newborns:	
Screened	99.2%
Refused	0.05%
Deceased	0.23%
Not screened	0.52%
Hearing Screening Results:	
Passed	98.4%
Referred	0.83%
Received diagnostic follow–up testing *(of newborns referred from screening)*	80.0%
Diagnostic results pending	20.0%
Diagnosed with a hearing loss *(% of 2005 births)*	0.18% (n=74)
Bilateral	n=32
Unilateral	n=42

Benefits of Early Hearing Detection & Intervention

⇒ Children born with a hearing loss who are identified and given appropriate intervention before 6 months of age demonstrate significantly better speech and reading comprehension than children identified after 6 months of age.

⇒ Early hearing detection followed by appropriate intervention minimizes the need for extensive habilitation during the school years and reduces the burden on the Individuals with Disabilities Education Act (IDEA) Part B program.

⇒ With appropriate early intervention, children with hearing loss can be mainstreamed in regular education classrooms.

Connecticut's Average Age of Diagnosis

National Goal = 3 months

Year	Age Diagnosed (in months)
2000	1.69
2001	3.06
2002	1.78
2003	1.38
2004	2.63
2005	2.79

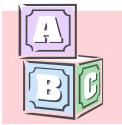
Early Intervention Services in Connecticut

Children identified with any degree of hearing loss are referred by the diagnosing audiologist to Child Development InfoLine (CDI). CDI staff triage the calls and refer eligible children to the Connecticut Birth-to-Three system.

Birth-to-Three has three specialty centers that work with infants and children who are deaf and hearing impaired and offer services to assist with children's communication skills, learning, and development. Research demonstrates that the sooner children with hearing loss are enrolled in early intervention the more positive their developmental outcomes .

Connecticut Average Age at Enrollment in Birth-to-Three
National Goal = 6 months

Year	Age at Enrollment (in months)
2000	2.13
2001	3.44
2002	2.64
2003	3.23
2004	3.83
2005	4.01

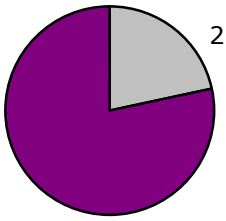


CT Birth-to-Three Eligibility

Children with a bilateral, 40 dB or greater hearing loss are **automatically** eligible for Birth-to-Three services upon diagnosis.

Children with a unilateral hearing loss or a bilateral hearing loss that is mild in at least one ear are not automatically eligible for services, but may be referred for an evaluation and found eligible if a developmental delay is present.

Birth-to-Three Eligibility Status of Infants with Hearing Loss, 2005



Why is this a concern?

Children with a unilateral hearing loss…

- have difficulty hearing speech if spoken to from behind or with background noise
- have difficulty localizing speech
- 35% repeat one or more grades, typically 1st
- 27%, ages 1 to 3, present with language delay

Children with a mild hearing loss…

- will miss 25-40% of what's said and 50% in noisy situations
- may not hear certain consonants
- cannot hear plurals or contractions
- 37% repeat a grade, typically 1st

Genetics and Hearing Loss

- Genetic testing can assist in establishing an etiologic diagnosis for the hearing loss.
- The GJB2 gene (Connexin defects) are responsible for more than half of the genetic causes of profound deafness in the United States.
- There are various ways genes that cause congenital hearing loss can be inherited.
- Genetic factors are associated with seventy percent of congenital cases of hearing loss. Of this group...
  - 30% are syndromic, cases in which deafness can be diagnosed because of associated clinical findings or syndromes.
  - 70% are classified as nonsyndromic and may be caused by a single gene mutation.
- Early identification of patients with certain forms of syndromic deafness can dramatically alter the risk of serious complications for the affected infant and other family members.

Past EHDI Program Highlights

► **Conducted provider survey,** 2005

- 98.6% knew that newborns are screened for hearing loss at birth
- 89.5% confirm the hearing screening was completed at the baby's first well-baby visit

► **Conducted parent survey,** 2005

- 92% confirmed that their baby had a hearing screening before discharge
- 81% stated that they understood the results of the screen
- 72% said hearing screening was not discussed during pre-natal care visits
- 40% reported that it was very stressful to learn that their infant did not pass the screen
- 80% understood that a referral from the screen did not necessarily mean that their baby was deaf

▪ Conducted three presentations at the annual CDC/MCHB **2006 National Early Hearing Detection and Intervention Conference in Washington, D.C.,** February 2-3, 2006

- *Factors that Influence Provider Discussion of Genetic Testing with Families of Infants with Hearing Loss*
- *Reaching Out to Professionals: Workshop Development*
- *The Impact of the Lack of Early Intervention for Infants with Hearing Loss*

▪ **Sponsored two educational conferences,** Fall 2005:

- *Newborn Hearing Screening Symposium* - co-sponsored by the University of Connecticut, Department of Communication Sciences. CEUs were available to participating audiologists.
- *Public Health Initiatives for Newborns* - offered as an educational opportunity for Connecticut hospital staff involved with newborn screening.

▪ **Presented at annual Connecticut Ear, Nose, and Throat Association meeting,** Fall 2005

▪ Health Resources and Services Administration (HRSA) **Universal Newborn Hearing Screening Grant award** received for September 1, 2005 - August 31, 2008

▪ **Program staff served as President of the Directors of Speech & Hearing Programs in State Health and Welfare Agencies** (DSHPSHWA) national organization

▪ **Funded Grand Round presentations** at area hospitals to educate providers on newborn screening and genetics, 2004-2005

▪ **Identified 17 diagnostic centers** that meet standards for infant audiological evaluation, 2002-2005

▪ **Standardized hearing screening methods in all birth hospitals,** 2002-2005

- Provided funding to four hospital neonatal intensive care units (NICUs) to purchase Automatic Brainstem Response (ABR) screening equipment to assure that all high risk infants receive an ABR screen prior to hospital discharge.

Upcoming Activities

Spring 2006

Listen & Learn Program to provide family education and follow-up speech, language and audiological services for infants with hearing loss who are not eligible for Birth-to-Three services

Fall 2006

2nd Annual Hearing Symposium

Provider training on Newborn Screening & Genetics, co-sponsored by the University of Connecticut Division of Human Genetics - CME units will be offered

Ongoing

Pediatric Grand Round presentations

Increased provider education on monitoring the hearing status of infants with risk factors

CONNECTICUT DEPARTMENT OF PUBLIC HEALTH

Keeping Connecticut Healthy

Commissioner J. Robert Galvin, MD, MPH

Early Hearing Detection and Intervention Program
410 Capitol Avenue,
P.O. Box 340308, MS# 11 MAT
Hartford, CT 06134-0308
Voice: 860 509-8057 / TTY: 860 509-7191
Fax: 860 509-8132
Web: http://www.dph.state.ct.us/bch/EHDI.htm

Screening before **1** month

Diagnosis before **3** months

Early Intervention before **6** months