

# MAINE STATE LEGISLATURE

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**Maine Newborn Hearing Screening Advisory Board  
Annual Report to the Legislature for 2010  
EXECUTIVE SUMMARY  
April, 2011**

**Background**

The 119<sup>th</sup> Maine State Legislature passed Public Law 647, 22 M.R.S.A. c. 1686, establishing the Maine Newborn Hearing Program (MNHP) within the Department of Health and Human Services, the Maine Center for Disease Control and Prevention, Division of Family Health. The intent of the original legislation was “to enable children and their families and caregivers to obtain information regarding hearing screening and evaluation and to learn about treatment and intervention services at the earliest opportunity in order to prevent or mitigate developmental delays and academic failures associated with undetected hearing loss.” The Newborn Hearing Screening Advisory Board was created to provide oversight and advice to the MNHP.

**Purpose**

The primary goals of the Newborn Hearing Screening Program are to ensure that: 1) All Maine newborns will be screened for hearing loss by one-month of age, preferably before hospital discharge; 2) All Maine infants who screen positive will have a diagnostic audiological evaluation before 3 months of age; 3) All Maine infants identified with hearing loss will receive appropriate early intervention services (medical, audiology, and early intervention) before six months of age; 4) All Maine infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time; 5) All Maine infants with hearing loss will have a medical home; and, 6) Maine will have a complete Early Hearing Detection and Intervention (EHDI) tracking and surveillance system that will minimize loss to follow-up.

**Highlights**

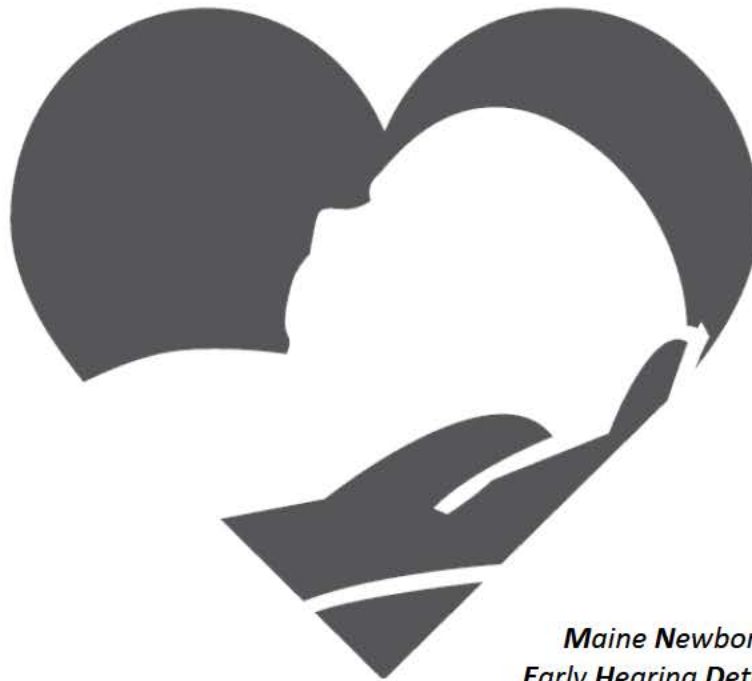
This 2010 Annual Report summarizes the current activities of the Maine Newborn Hearing Program and the Advisory Board, as well as ongoing and upcoming activities of the Program and Board for 2011. It also shows MNHP progress toward ensuring that every infant born in Maine is provided a hearing screen and that those identified with a possible hearing loss are referred for an audiological diagnostic evaluation. Some of the activities that the Maine Newborn Hearing Program undertook in 2010 were working with all birthing facilities to provide hearing screening and scheduling diagnostic appointments, receiving the Maine Public Health Association's Program of Excellence Award for 2010, and sponsoring two conferences on pediatric audiology and early intervention.

In 2011, the Maine Newborn Hearing Program will continue to improve the loss to follow-up/documentation rates by participating in a quality improvement project and working with Maine nurse midwifery practices to expand opportunities for babies born at home to receive hearing screens.

**For more information on activities of the Maine Newborn Hearing Program:**

Contact Betsy Glencross, Program Coordinator, [betsy.glencross@maine.gov](mailto:betsy.glencross@maine.gov) or 207-287-8427  
[http://www.maine.gov/dhhs/boh/cshn/hearing\\_screening/index.html](http://www.maine.gov/dhhs/boh/cshn/hearing_screening/index.html)

# Maine Newborn Hearing Screening Advisory Board 2010 Annual Report



*Maine Newborn Hearing Program  
Early Hearing Detection and Intervention*

Maine Newborn Hearing Program Advisory Board  
Maine Department of Health and Human Services, Maine Center for Disease Control and  
Prevention, Division of Family Health, Children with Special Health Needs

April, 2011

Joint Standing Committee on Health and Human Services  
#100 State House Station  
Augusta ME 04333-0100

Dear Members of the Joint Standing Committee on Health  
and Human Services:

The Maine Newborn Hearing Advisory Board is pleased to  
present to you the 2010 annual report for Maine's Newborn  
Hearing Program (MNHP). This report covers the efforts of  
MNHP from January 1, 2010 – December 31, 2010.

The Maine Newborn Hearing Program's Advisory Board is  
comprised of individuals from a wide variety of  
backgrounds and regions across Maine. The Board's  
mission is to advise the Maine Newborn Hearing Program  
and the DHHS Commissioner of issues relating to the  
program and make recommendations for hearing screening,  
evaluations, treatment and intervention procedures.

This year marks the 10<sup>th</sup> Anniversary of the Maine  
Newborn Hearing Program. The dedication of the staff over  
the past 10-years has shown a marked increase in the  
number of infants screened each year. In 2000, less than ¼  
of the infants in Maine were screened for hearing loss and  
only three of our 30 birth facilities provided any screening  
at all. Today 98% of infants born in Maine are screened for  
hearing loss.

We remain committed to the idea that all of Maine's  
newborns should have a hearing screening and be linked to  
appropriate early intervention services as soon as possible  
when identified with a hearing loss.

Sincerely,

Carrie Chojnowski and Annette Bowman

Co-chairpersons

Maine Newborn Hearing Program Advisory Board

The members of the Maine  
Newborn Hearing Advisory  
Board:

Eileen Peterson

Stephen Meister

Louise Packness

Nola Metcalf

Karen Perry

Karen Hopkins

Romy Spitz

Jennifer Libby

Kristen Shorey

Annette Bowman

Karen Harrison

Gail Donahue

Lisa Sockabasin

Carrie Chojnowski

Harriet Gray

Matthew Hearst

Bethany Picker

## Summary

The 119<sup>th</sup> Maine State Legislature enacted 22 M.R.S.A. c. 1686, establishing the Maine Newborn Hearing Program (MNHP) within the Department of Health and Human Services, the Maine Center for Disease Control and Prevention, Division of Family Health. The intent of the original legislation was “to enable children and their families and caregivers to obtain information regarding hearing screening and evaluation and to learn about treatment and intervention services at the earliest opportunity in order to prevent or mitigate developmental delays and academic failures associated with undetected hearing loss.” The primary goals of the Newborn Hearing Screening Program are to ensure that:

- All Maine newborns will be screened for hearing loss by one-month of age, preferably before hospital discharge;
- All Maine infants who screen positive will have a diagnostic audiological evaluation before 3 months of age;
- All Maine infants identified with hearing loss will receive appropriate early intervention services (medical, audiology, and early intervention) before six months of age;
- All Maine infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time;
- All Maine infants with hearing loss will have a medical home; and,
- Maine will have a complete Early Hearing Detection and Intervention (EHDI) tracking and surveillance system that will minimize loss to follow-up.

Since January 2003, every birthing facility in Maine has been required to report to the Maine Newborn Hearing Program (MNHP) the number of babies born in the facility, the number of newborns who received a hearing screen, the number who passed and did not pass the screening, and the number of newborns whose parents declined hearing screening. Each of these birthing facilities can upload information electronically directly into the data tracking system, ChildLINK. Hospital IT staff and ChildLINK personnel worked together to establish this data linkage, thereby reducing the burden of manually inputting data. This connection has resulted in a more effective and efficient system, not only for the hospital personnel, but also allows for timely interventions for families whose infants “did not pass” a newborn hearing screen.

An electronic data tracking system, ChildLINK, links newborn hearing screening data with the electronic birth certificate, enabling the MNHP to verify that every baby born in Maine has a newborn hearing screen and to track follow-up services regarding audiological diagnostic evaluations and referrals to and participation in early intervention services.

This report includes an overview of the previous year’s activities, counts of the number of children screened and evaluated and of those children being offered and receiving early intervention services.

## Introduction

Every day, 33 babies (or 12,000 each year) are born in the United States with permanent hearing loss. Hearing loss is one of the most common birth defects. According to the Joint Committee on Infant Hearing, “hearing loss in newborns is not readily detectable by routine clinical procedures.” In 1992, a Consensus Panel convened by the National Institutes of Health concluded “that all infants should be screened for hearing impairment. This will be accomplished most efficiently by screening prior to hospital discharge. Infants who fail a screen should have a comprehensive hearing evaluation no later than 6-months of age.”

Historically, hearing loss often went undetected until a child began to experience delays in language development. If hearing impaired children are not identified early, it is difficult, if not impossible, for many of them to acquire fundamental language, social and cognitive skills that provide the foundation for later schooling and success in society. Research has shown that the most critical period for speech and language development is from birth to age three. Without newborn hearing screening, the average age of identification of congenital hearing loss is 2 ½ to 3 years of age, well beyond the most critical period for language development. The resulting delays in fluent language and communication capabilities can have a lifelong impact on the individual and can result in significant and irreversible cognitive and social delays.

In 2000, the Department of Health and Human Services established the Maine Newborn Hearing Program. Additional amendments to the MNHP legislation include:

- LD 1142, “An Act to Enhance the Newborn Hearing Program” which became law in September 2007 and mandates that all providers of hearing diagnostic procedures report the results of their evaluation and diagnosis to the MNHP;
- LD 2106 “An Act to Enhance the Newborn Hearing Program” which was signed into law and became effective in July 2008. This law allows the MNHP to participate in a regional database with the other New England states to share hearing screening, evaluation and intervention data for those children who did not receive those services in their birth state; and
- LD 2295, “An Act to Implement the Recommendations of the Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine” was signed into law and became effective in July 2008. This law requires that, when a newborn receives a newborn hearing screening result of “refer,” the facility that performed the screening shall schedule the newborn for a follow-up appointment with an audiologist.

## Maine Newborn Hearing Program's Reportable Data

The data system for the Maine Newborn Hearing Program is provided by the University of Maine at Orono through a cooperative agreement first established in October 2004. ChildLINK is a data tracking system that links newborn hearing screening data with multiple data sources including electronic birth certificates, death certificates, bloodspot screening data, and audiological evaluation results. Some of the pertinent information captured by ChildLINK include:

- the number of births,
- the number of newborns screened for hearing loss,
- the number of infants who passed the newborn hearing screen,
- the number of infants referred for audiological diagnostic evaluation,
- the number of infants with confirmed hearing loss, and
- the number of infants referred for early intervention services.

Tremendous progress has been made since the establishment of the Newborn Hearing Program in 2000. In 2000, less than one-quarter of the infants in Maine were screened for hearing loss. Information received for children born in Maine in 2009 indicates that 98% of all newborns were screened for hearing loss with a 2% referral rate.

Newborn Hearing Screening Reportable Data January 1, 2009 – December 31, 2009		
	Number	Percentage
Births	13,353	
Infants Screened	13,054	98%
Infants not screened	299	2%
Missed screening*	238	
Infant died	48	
Parents declined services	13	
*“Missed” means that the newborn was not screened or missed due to reasons other than death or refusal		
Results of Newborns Screened (N = 13,054 )		
Newborns whose screening results were “pass”	12,813	98%
Newborns whose screening results were “refer”*	241	2%
*“Refer” means that the newborn did not pass the screening and was referred to an audiologist for additional diagnostic evaluations.		
Results of Newborns who “refer” (N = 241 )		
Audiological diagnostic evaluation	138	57%
Hearing normal	110	
Hearing loss	12	
Diagnostic evaluation in process	16	
Passed/Missed screening-MNHP received report of hearing loss	6	
Results of Newborns who referred on hearing screen and diagnosed with hearing loss (N = 12 )		
Children diagnosed with hearing loss and MNHP received confirmation of enrollment in Part C-Early Intervention	3	25%

## **Funding Sources: Who Pays for Universal Newborn Hearing Screening?**

Since 1999, the Federal Centers for Disease Control and Prevention continue to support the Maine Newborn Hearing Program through cooperative agreements. These funds have been used to support MNHP state office personnel and development and continued enhancement of the data tracking system, ChildLINK. MNHP also receives funding (through grant awards) from the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau, Division of Children with Special Health Care Needs Program. The original funds were used to purchase screening equipment for hospitals in Maine to screen all newborns beginning in 2004. MNHP continues to receive grant funding from HRSA, and these funds have allowed MNHP to provide educational resources to parents, training to professionals, support for Hands & Voices Maine and to purchase the services of a Parent Coordinator, Follow-up Coordinator, and Audiologist.

## **Key Accomplishments in 2010**

### **GENERAL PROGRAM AND BOARD ACTIVITIES**

- MNHP was selected to receive the Maine Public Health Association's Program of Excellence Award for 2010.
- MNHP Advisory Board met four times.
- Hired a full-time Follow-up Coordinator.
- Disseminated over 20,000 brochures and other informational materials to birthing facilities, health professionals, families and other interested parties.

### **SCREENING**

- Provided hearing screening assistance to birthing facilities, as appropriate, including establishing and following protocols, staff training, and technical support.
- Collaborated with midwifery practices in Maine to provide newborn hearing screening.

### **RISK FACTORS AND MEDICAL HOME**

- Participated in the National Initiative for Children's Healthcare Quality Learning Collaborate (NICHQ), established goals of identifying the child's primary care provider prior to hearing screen and in improving identification of children with known risk factors for late onset, progressive or acquired hearing loss, and continued our partnership with Eastern Maine Medical Center to pilot this work.
- Appointed a pediatrician to serve as our American Academy of Pediatrics (AAP) Chapter Champion whose role is to help focus on increasing the involvement of primary care pediatricians and other child health care providers.

### **AUDIOLOGY**

- Sponsored a Pediatric Audiology Conference attended by 25 Maine audiologists.

### **EARLY INTERVENTION**

- Sponsored an Early Intervention Conference attended by over 90 participants.
- Met quarterly with staff from the Department of Education, Child Development Services and the Maine Educational Center for the Deaf and Hard of Hearing to discuss early intervention services.
- A Memorandum of Agreement between the Departments of Education and Health and Human Services was signed.



#### **FAMILY SUPPORT**

- Supported the establishment of a state chapter of Hands & Voices, a non-profit organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them.

#### **DATA TRACKING AND SURVEILLANCE**

- Completed a system wide evaluation of the newborn hearing screening program using the CDC's Guidelines for Evaluating Public Health Surveillance Systems.

### **Planned Activities for 2011**

#### **GENERAL PROGRAM AND BOARD ACTIVITIES**

- Work with the Advisory Board to evaluate the cultural sensitivity of the educational materials provided by the MNHP.

#### **SCREENING**

- Create a hearing screening training module for birthing facilities which will include standard scripts for screeners and health care providers to use when communicating with parents about the hearing screen, results and follow-up.
- Work with Maine nurse midwifery practices to expand opportunities for babies born at home to receive a hearing screen.

#### **RISK FACTORS AND MEDICAL HOME**

- Implement the work done with EMMC and the NICHQ learning collaborative to other hearing screening facilities.

#### **AUDIOLOGY**

- Provide educational training/support to pediatric audiologists in Maine.
- Work with rural health providers to develop a plan to provide audiological testing and evaluation in rural and underserved areas of the State.

#### **EARLY INTERVENTION**

- Provide site visits to all Child Development Services sites to educate about the role of the MNHP.
- Continue to develop the protocols for referrals to Child Development Services as designated in the Memorandum of Agreement signed in 2010.

#### **FAMILY SUPPORT**

- Establish a Hands & Voices Maine Guide-By-Your-Side Program. This program is designed to provide the unique support of experienced families of children who are deaf, hard of hearing and deaf/blind to families at the time of their child's identification of hearing loss, as well as at other crucial times throughout the parenting years.

#### **DATA TRACKING AND SURVEILLANCE**

- Implement recommendations made by the stakeholder's group from the evaluation of the comprehensive screening and service system.