Department of Health and Human Services
Maine People Living Safe, Healthy and Productive Lives
Paul R. LePage, Governor Mary C. Mayhew, Commissioner

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February 7, 2012

Senator Earle L. McCormick, Chair
Representative Meredith N. Strang Burgess, Chair
Joint Standing Committee on Health and Human Services
#100 State House Station
Augusta, ME 04333-0100

Dear Senator McCormick and Representative Strang Burgess and Members of the Joint Standing Committee on Health and Human Services:

Attached please find the *2011 Annual Report to the Legislature of the Maine Newborn Hearing Screen Advisory Board* submitted on the Board's behalf by the Department of Health and Human Services. This report is required under 22 M.R.S.A. §8823(1)(B). The report discusses the Board's and the Maine Newborn Hearing Program's activities and accomplishments in 2011, as well as planned activities for 2011.

Thank you for the opportunity to provide you with a report on the activities and accomplishments of the Maine Newborn Hearing Program and of the Newborn Hearing Screening Advisory Board.

Sincerely,

Mary C. Mayhew
Commissioner

MCM/klv

Attachment

Maine CDC Newborn Hearing Program

January 1, 2011 – December 31, 2011

Submitted to the Joint Standing Committee on Health and Human Services

2011 Annual Report

December 31, 2011

Senator Earle L. McCormick, Chair
Representative Meredith N. Strang Burgess, Chair
Joint Standing Committee on Health and Human Services
100 State House Station
Augusta, ME 04333-0100

Dear Senator McCormick and Representative Strang Burgess;

The Maine Newborn Hearing Advisory Board is pleased to present to you the 2011 Annual Report for the Maine CDC Newborn Hearing Program. This report covers the efforts of the Maine CDC Newborn Hearing Program from January 1, 2011 – December 31, 2011.

The Maine Newborn Hearing Advisory Board is comprised of individuals from a wide variety of backgrounds and regions across Maine. The Board's mission is to advise the Department of Health and Human Services and make recommendations to the Commissioner on issues relating to the Maine CDC Newborn Hearing Program for hearing screening, evaluation, treatment and intervention procedures.

The Advisory Board as well as the staff of the Maine CDC Newborn Hearing Program continue to be dedicated to increasing the number of infants screened for hearing loss and reducing the number of infants who are lost to follow-up. In 2000, less than 25% of the infants in Maine were screened; today, 98% percent 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 approriate early intervention services as soon as possible when identified with a hearing loss.

Sincerely,

Annette Bowman and Romy Spitz, Co-Chairs
Maine Newborn Hearing Advisory Board

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EXECUTIVE SUMMARY
January 2012

Background

The 119th Maine State Legislature passed Public Law 1999, c.647, adopted under the authority of 22 MSRA c. 1686, §8821-8825 establishing the Maine CDC Newborn Hearing Program (MNHP) within the Department of Health and Human Services. The Program is currently housed within the Maine Center for Disease Control and Prevention, Division of Population Health, Children with Special Health Needs Program. 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."

Purpose

The Maine CDC Newborn Hearing Program (NHP) is tasked with achieving progress on seven national goals that lead to a comprehensive coordinated early hearing detection and intervention program. Each of the national goals has specific objectives and measures allowing Maine CDC NHP to track their progress.

Goal 1: All infants will be screened for hearing loss by one month of age, preferably before hospital discharge.
Goal 2: All infants who screen positive will have a diagnostic audiological evaluation before three months of age.
Goal 3: All infants identified with a hearing loss will begin receiving appropriate early intervention services before six months of age.
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.
Goal 6: The Program will have a complete Early Hearing Detection and Intervention (EHDI) tracking and surveillance system that will minimize the loss to follow-up.
Goal 7: The Program will have a comprehensive system that monitors and evaluates the progress toward the preceding six goals.

Highlights

In this 2011 Maine CDC Newborn Hearing Annual Report, the Advisory Board describes the role and activities of the Maine CDC Newborn Hearing Program (NHP) as well as any associated legislation, statistics related to screening, follow-up and access to early intervention, challenges and recommendations.

For more information on the Maine CDC Newborn Hearing Program: *Contact Betsy Glencross, Newborn Hearing Coordinator, betsy.glencross@maine.gov or 207-287-8427*
www.mainepublichealth.gov/MNHP

Maine CDC Newborn Hearing Program Overview

Background

The purpose of the Maine CDC Newborn Hearing Program (NHP) is to support early identification and timely and appropriate intervention for hearing loss. The Maternal and Child Health Bureau, the Joint Committee on Infant Hearing, the American Academy of Pediatrics, and the U.S. Centers for Disease Control and Prevention have provided national goals to each state's Early Hearing Detection and Intervention Programs (EHDI), which in Maine is called the Maine CDC Newborn Hearing Program. These national goals have been established to ensure hearing screening for all newborns no later than one month of age, diagnostic audiological evaluations as early as possible but no later than three months of age for those who do not pass the screening and enrollment in early intervention services, as early as possible but no later than six months of age for those identified with hearing loss.

Legislation and Rules

Legislation supporting the Maine CDC Newborn Hearing Program has and continues to define the purpose of the Program, activities associated with screening, audiologic evaluation and early intervention services, and designates who is responsible for these activities. The statutes defining these roles and responsibilities are listed below.

March 1999, Public Law1999, c.647, adopted under the authority of 22 MSRA c. 1686, §8821-8825, establishes the Maine Newborn Hearing Program (NHP) within the Department of Health and Human Services. Program rules were adopted January 2004 defining the responsibilities of birthing facilities, primary healthcare providers, audiologists, and Maine CDC NHP.

Amendments to this legislation are as follows:

September 2007, all providers of hearing diagnostic procedures are mandated to report the results of their evaluation and diagnosis to the Maine CDC NHP for children up through the age of 3 years.

July 2008, the Maine CDC NHP is allowed 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.

July 2008, all facilities that screen for hearing loss are mandated to schedule the newborn for a follow-up appointment with an audiologist when the infant does not pass the hearing screen.

September 2009, the Maine CDC Newborn Hearing Program is required to refer all children identified with a confirmed hearing loss to the Department of Education's Child Development Services Part C Early Intervention Program.

Stakeholders

The following is a brief listing of organizations that have a strong association with the Maine CDC Newborn Hearing Program.

• **Consumers** ○ Parents and families ○ People who are deaf or hard of hearing	• **Early Intervention Agencies** ○ Department of Education – Child Development Services ○ Maine Educational Center for the Deaf and Hard of Hearing – Early Childhood and Family Services
• **External groups involved with screening, follow-up and diagnosis** ○ Hospitals and their staff (i.e. screeners) ○ Audiologists ○ Nurses ○ Primary care providers ○ Specialty physicians ○ Genetic Counselors	• **Other State Programs** ○ Maine CDC Birth Defects Program ○ Maine CDC Newborn Bloodspot Screening Program ○ Maine CDC Data, Research and Vital Statistics ○ Office of MaineCare

State Advisory Board

The Maine Newborn Hearing Advisory Board was created by the 119th Maine State Legislature through the enactment of Public Law 1999,c 647, 22 M.R.S.A. c. 1686.

The Board consists of an odd number of members, appointed by the Governor, including but not limited to: an audiologist, a physician, a speech-language pathologist, a nurse, a certified teacher of the deaf, a person who provides early intervention services to children who are deaf or hard of hearing through the Maine Educational Center for the Deaf and Hard of Hearing, a person who is culturally deaf, a person who is hard-of-hearing or deaf, a parent of a child who is culturally deaf, a parent of child who is hard-of hearing or deaf, a parent of a hearing child and a representative of hospitals, health carriers, early childhood special education program under Title 20-A, Chapter 303 and a representative of the Department.

The purpose and duties of the Board, as set forth in statute, are to:

- Oversee the Maine CDC Newborn Hearing Program;
- Advise the Commissioner of the Department of Health and Human Services on issues relating to the Maine CDC Newborn Hearing Program;
- Make recommendations on the procedures for hearing screening, evaluation, treatment and intervention services; and,
- Submit an annual report on the percentages of children being screened and evaluated and those children being offered and receiving intervention and treatment services.

MNHP Advisory Board Members
December 31, 2011

Audiologist – Eileen Peterson	**Physician** – Stephen Meister
Speech-Language Pathologist – Louise Packness	**Nurse** – Nola Metcalf
Certified Teacher of The Deaf – Donna Casavant	**ECFS EI Service Provider** – Karen Hopkins
Culturally Deaf Person – Vacant	**Hard-of-Hearing or Deaf Person** – Romy Spitz (Co-Chair)
Parent of a child who is culturally Deaf – Vacant	**Parent of a hard-of-Hearing or Deaf Child** – Jennifer Libby
Parent of a Hearing Child – Kristen Shorey	**Representative of Hospitals** – Annette Bowman (Co-Chair)
Representative of Health Insurance Carriers – Karen Harrison	**Representative of CDS** – Gail Donahue
Representative of DHHS – Lisa Sockabasin	**Other** – Carrie Chojnowski
Other – Harriet Gray	**Other** – Matthew Hearst
Other – Bethany Picker	

Summary of Activities

- The Maine CDC NHP Advisory Board met two times.
- The Board began reviewing and updating the educational materials provided by the Maine CDC NHP.
- The Board began to review its by-laws/guidelines.
- The Board learned more about the risk factors for late onset, acquired or progressive hearing loss, the recommended follow-up protocols and the challenges faced by the Maine CDC NHP in tracking babies who have these risk factors.

Maine CDC Newborn Hearing Program Summary

Program Description

According to the Joint Committee on Infant Hearing, hearing loss often has no visual indicators and is not easily detected in newborns. Hearing loss is one of the most common birth defects. Historically, hearing loss often went undetected until a child began to experience delays in language development. At this point, parents and professionals began to seek answers and often found the language delay was related to an undiagnosed hearing loss.

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 diagnosis is 2 ½ to 3 years of age. The resulting delays in fluent language and communication can have a lifelong impact on the child with significant and irreversible cognitive and social delays.
In 1999 the Maine State Legislature addressed these concerns by establishing the Maine CDC Newborn Hearing Program within the Department of Health and Human Services, Maine Center for Disease Control and Prevention, Division of Family Health.

Funding Sources

The Maine CDC Newborn Hearing Program is funded entirely through the Federal U.S. Department of Health and Human Services; the Federal Centers for Disease Control and Prevention awarded Maine CDC NHP a five-year grant (2011 – 2016) for the "Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs" and the Maternal and Child Health Bureau, Division of Children with Special Health Care Needs Program awarded the Maine CDC NHP a three-year grant (2011 – 2014) to "Reduce the Loss to Follow-up after Failure to Pass Newborn Hearing Screening."

Personnel

The Maine CDC Newborn Hearing Program consists of one full-time Hearing Coordinator and a full-time Office Associate II (currently vacant). The federal grants have allowed Maine CDC NHP to contract with a full-time Follow-up Coordinator, a part-time Parent Consultant, a part-time Audiologist and support for the data, tracking and information system called "ChildLINK."

Goals, Activities and Achievements

The primary goal of the Maine CDC Newborn Hearing Program is "to develop and sustain a comprehensive coordinated system for early hearing detection intervention (EHDI) in Maine in which hospitals, primary care providers, audiologists, allied health professionals, and others work together to ensure that infants with hearing loss are identified early and appropriate early intervention services be initiated without delay. Without early identification and intervention children with hearing loss could experience delays in the development of language.

The six goals of the Maine CDC Newborn Hearing Program are to ensure that:

1. All Maine newborns are screened for hearing loss by one-month of age, preferably before hospital discharge;
2. All Maine infants who screen positive have a diagnostic audiological evaluation before 3-months of age;
3. All Maine infants identified with hearing loss receive appropriate early intervention services (medical, audiological, and early intervention) before 6-months of age;
4. All Maine infants and children with late onset, progressive or acquired hearing loss 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.

Maine CDC Newborn Hearing Tracking System

Tracking System

Maine CDC NHP began collaborating with the University of Maine at Orono in 2000 to develop and implement a comprehensive surveillance and tracking system. Today, ChildLINK tracks

approximately 13,000 infants born in Maine each year. ChildLINK links hearing screen data with multiple data sources that include birth and death certificates, metabolic screen data, audiology evaluation reports, and birth defects data. ChildLINK maintains security/confidentiality of all records by assigning permission to access the system on an individual basis. Access is monitored by Symantec on a 24/7 basis.

Process Overview

The system links multiple data sources that include but are not limited to electronic birth and death certificates, bloodspot screening data, newborn hearing screening data, birth defects (hospital discharge and abstraction information), and audiologic diagnostic reports. While no formal mechanism exists for routinely collecting information from all early intervention programs, whenever possible, MNHP staff gathers select intervention information on children with hearing loss.

Statistical Reports

Maine CDC Newborn Hearing Program Data

Criteria	Number (%)				
	2005	2006	2007	2008	2009**
Number of Births	13988	14009	13975	13500	13353
Total screened all births	13169 (94%)	13549 (96.7%)	13602 (97%)	13178 (98%)	13054 (98%)
Screened by age 1 month	12825	13189	13560	13060	12812
Not screened	819 (6%)	460 (3.3%)	373 (3%)	322 (2%)	299 (2%)
Infant died or parents declined services	80	83	97	82	61
Missed screening	739	377	276	240	238
Pass screening	12895 (98%)	13219 (97.6%)	13310 (98%)	12979 (98.5%)	12813 (98%)
Refer screening	274 (2%)	330 (2.4%)	292 (2%)	199 (1.5%)	241 (2%)
Referred on screening-MNHP received audiological report	94 (34%)	112 (33.9%)	146 (50%)	137 (69%)	138 (57%)
Hearing normal	47	78	126	93	110
Hearing loss	21	14	20	18	12
Diagnosis in progress	26	20	13	26	16
Unknown (LTF)	178 (65%)	194 (63.6%)	138 (47%)	62 (30%)	101 (42%)
Hearing Loss diagnosed, MNHP received confirmation of enrollment with Part C provider-CDS	2	3	6 (30%)	7 (39%)	3 (25%)

**Maine CDC NHP was required to change the data reporting criteria in 2009 to comply with CDC-EHDI reporting on most recent hearing screen result to be reported. (if both ears were not screened and passed in most recent hearing screen, baby is reported as not pass screening which was not the hearing screening protocol for Maine at that time.) This caused a slight increase in refer rate (and associated Audiology reporting rate) which is reflected in 2009.

Public Awareness

Education and Informational Materials

The Maine CDC Newborn Hearing Program provides a variety of materials for families of children with hearing loss. These materials are available at no cost. The materials include:

For Hearing Screening: The booklet *Hearing in Infants and Young Children* is provided to all families whose child is born in Maine.

For Audiologic Diagnosis: The Program provides three booklets that provide basic information about hearing loss. Audiologists are the main source for distribution of these booklets:

- *Resource Guide for Families of Children with Hearing Loss*
- *Resource Guide for Families of Children with Mild Hearing Loss*
- *Resource Guide for Families of Children with Unilateral Hearing Loss*

For Early Intervention: The Program provides a notebook, *A Parent's Guide for Infants & Children with Hearing Loss*. Early intervention services (Child Development Services and Early Childhood and Family Services) are the main source for provision of this notebook. It is the intention of the Program that every family of every child in Maine who is diagnosed with hearing loss receives one of these books.

Website

www.mainepublichealth.gov/MNHP

Maine CDC Newborn Hearing Program
Key Accomplishments in 2011

General Program Activities

- 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 which includes establishing and following protocols, staff training, and technical support.
- In 2010, there were 214 home births in Maine and only 36 of these babies were screened for hearing loss at birth. To address this disparity, the Program provided screening equipment and support to a large midwifery practice for screening babies born at home.

Audiology

- Consulted with and provided training and support to several new audiologists to ensure that they were aware of Maine's Pediatric Audiology Guidelines.
- Consulted with Maine audiologists to ensure that MNHP received diagnostic reports on all children birth through three years of age.

Risk Factors and Medical Home

- Continued to work with screening facilities on identifying children with known risk factors for late onset, acquired or progressive hearing loss.
- Worked with Maine CDC NHP's Chapter Champion, a pediatrician whose role is to help focus on increasing the involvement of primary care pediatricians and other health care providers.
    - Participated in communications with the Region I Chapter Champions and EHDI Coordinators in developing the American Academy of Pediatrics (AAP) EHDI Task Force Strategic Plan.
    - Collaborated with the Maine Chapter of AAP in applying for an AAP EHDI Education and Training Award. At this writing our application was not awarded funding.

Early Intervention

- 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.
- Initiated meetings with each of the nine Child Development Services sites to increase knowledge of the Maine CDC NHP goals and purposes. To date, five sites have been visited.

Family Support

- Continued support to the development of Maine 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.
- Provided support to the 2011 Hands & Voices National Leadership Conference held in Portland, Maine in June. Over 200 people attended this conference.
- Supported the establishment of the Maine Guide-By-Your-Side Program (GBYS), an innovative program designed to provide emotional support and specialized knowledge from trained parents of children who are deaf or hard of hearing.
    - Maine GBYS was approved by National Hands & Voices in February.
    - An initial training for seven potential parent guides was provided in August.
- Sponsored a presentation for parents and professionals by Rachel Coleman, from Signing Time Productions in May. The program, "One Deaf Child" was attended by approximately 80 people.

Data Tracking and Surveillance

- Worked with other programs within the Maine CDC Children with Special Health Needs Section in updating and expanding the ChildLINK data tracking system in order to enhance the capacity of ChildLINK to integrate with other state screening, tracking and surveillance systems.
- Worked with Maine Audiologists to update the Maine Audiologic Assessment form in order to more efficiently track and report on diagnostics and follow-up for children who do not pass their newborn hearing screen.

Challenges and Future Direction

General Barriers to Success

- The current system of services in Maine for children with hearing loss is designed to serve infants with bilateral, severe/profound hearing loss but the majority of children identified with other degrees of hearing loss have difficulty obtaining needed support and services.
- The needs of the child and family are often lost in the 'process.' Families are often not given enough information or get conflicting messages from various resources or need help but do not know how to get it.

Screening

- Screening equipment is expensive to maintain and replace.
- Better training plan is needed for screening facilities.
- Low screen rate on home births. Screening equipment cannot be used in the home and is cost prohibitive for midwifery practices.
- Lack of information- many parents don't know that their babies were screened or the importance of early hearing screening.

Audiology

- Lack of access to services
  - Shortage of qualified pediatric audiologists.
  - Limited number of facilities statewide. There are only six pediatric audiology facilities in Maine serving only five counties.
  - Poor reimbursement rates for audiologists providing pediatric services.
  - Some providers refuse MaineCare clients.
- Many audiologists are still not consistently reporting diagnostic evaluations to the Program.
- Primary care providers often lack the knowledge about pediatric hearing loss and the importance of a complete pediatric audiologic evaluation on babies who do not pass the hearing screen.
- Families need more information and/or empowerment for services.

Risk Factors and Medical Home

- Screeners lack knowledge about the importance of reporting risk factors to the Program or lack access to this information.
- Primary Care Providers lack the knowledge on risk factors and the importance and timing of appropriate follow-up.
- The Program needs to develop a physician database that accurately reflects a child's physician beyond the newborn hearing screening and birth certificate period.
- Primary Care Providers often do not receive the hearing screen information and/or families do not have a primary care provider at the time of the hearing screen.

- Primary Care Providers are often not aware of the available/appropriate services for children with hearing loss.

Early Intervention

- Shortage of qualified service providers.
- Statewide options not available to families.
- Families must travel out of state to obtain a cochlear implant.

Future Direction

The overall future direction for the Maine CDC NHP and the Advisory Board is to assure that all infants are screened by 1-month, evaluated by 3-months and receive early intervention services by 6-months.

- Provide an annual report to hospitals on the total births, total screened, total referred, total with no screening results compared to hospitals overall in Maine.
- Assure access to early intervention services enrollment data by having Maine CDC NHP on the Department of Education's Child Development Services Release of Information Form.
- Maine CDC NHP develops protocols for tracking infant hearing screening, audiologic assessment and early intervention.
- Continue to work with MaineCare to assure that each infant receives a screen, assessment and early intervention services.
- Collaborate with the HeadStart, WIC and home visiting staff to increase knowledge of newborn hearing screening to reduce the loss to follow up.
- Continue quality improvement activities that increase efficiency at all levels.