

MAINE STATE LEGISLATURE

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January 23, 2013

Senator Margaret M. Craven, Chair
Representative Richard R. Farnsworth, Chair
Joint Standing Committee on Health and Human Services
#100 State House Station
Augusta, ME 04333-0100

Dear Senator Craven and Representative Farnsworth and Members of the Joint Standing Committee on Health and Human Services:

Attached please find the 2012 Annual Report to the Legislature for the Maine CDC Newborn Hearing Program submitted by the Department of Health and Human Services. This report is required under Title 22 of the M.R.S.A., Chapter 1686. The report discusses the Maine CDC Newborn Hearing Program's activities and accomplishments in 2012 as well as planned activities for 2013.

Thank you for the opportunity to provide the Joint Committee on Health and Human Services with a report on the activities and accomplishments of the Maine CDC Newborn Hearing Program.

Sincerely,

Mary C. Mayhew
Commissioner

MCM/klv

Attachment

Maine CDC Newborn Hearing Program



January 1, 2012 – December 31, 2012

Submitted to the Joint Standing Committee on Health and Human Services

2012 Annual
Report

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EXECUTIVE SUMMARY

January 2013

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. MNHP 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

MNHP 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 MNHP 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: MNHP will have a complete Early Hearing Detection and Intervention (EHDI) tracking and surveillance system that will minimize the loss to follow-up.

Goal 7: MNHP will have a comprehensive system that monitors and evaluates the progress toward the preceding six goals.

Purpose of this Report

In this 2012 MNHP Annual Report, the Advisory Board describes the role and activities of MNHP as well as any associated legislation, statistics related to screening, follow-up and access to early intervention, challenges and recommendations.

For more information on MNHP: 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 (MNHP) 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 MNHP has defined and continues to define the purpose of MNHP, 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 Law 1999, 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 MNHP.

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 MNHP for children up through the age of 3 years.

July 2008, MNHP 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, MNHP 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 listing of organizations that have a strong association with MNHP.

<ul style="list-style-type: none">● Consumers<ul style="list-style-type: none">○ Parents and families○ People who are deaf or hard of hearing	<ul style="list-style-type: none">● Early Intervention Agencies<ul style="list-style-type: none">○ Department of Education – Child Development Services○ Maine Educational Center for the Deaf and Hard of Hearing – Early Childhood and Family Services
<ul style="list-style-type: none">● External groups involved with screening, follow-up and diagnosis<ul style="list-style-type: none">○ Hospitals and their staff (i.e., screeners)○ Audiologists○ Nurses○ Primary care providers○ Specialty physicians○ Genetic Counselors	<ul style="list-style-type: none">● Other State Programs<ul style="list-style-type: none">○ 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 each of the following: hospitals, health carriers, early childhood special education program under Title 20-A, Chapter 303, and the Department.

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

- Oversee MNHP;
- Advise the Commissioner of the Department of Health and Human Services on issues relating to MNHP;
- 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, 2012**

Audiologist – Eileen Peterson, M.S., FAAA	Physician – Christopher Pezzullo, D.O.
Speech-Language Pathologist – Louise Packness, CCC-SLP	Nurse – Nola Metcalf, RN-C
Certified Teacher of The Deaf – Donna Casavant, MED, CAS	ECFS EI Service Provider – Karen Hopkins, M.Ed. CAGS
Culturally Deaf Person – Vacant	Hard-of-Hearing or Deaf Person – Romy Spitz, Ph.D. (Co-Chair)
Parent of a child who is culturally Deaf – Vacant	Parent of a hard-of-Hearing or Deaf Child – April Morin
Parent of a Hearing Child – Kristen Shorey, M.Ed.	Representative of Hospitals – Annette Bowman, RN
Representative of Health Insurance Carriers – Karen Harrison (Co-Chair)	Representative of CDS – Gail Donahue, Ph.D., CCC-SLP
Representative of DHHS – Vacant	Other – Carrie Chojnowski, M.S., CCC-SLP, LSLS/Cert. AVT
Other – Harriet Gray, Ph.D.	Other – Matthew Hearst, MD
Other – Bethany Picker, M.D.	

The Board is aggressively seeking prospective members to fill current vacancies.

Summary of Activities

During 2012, MNHP Advisory Board met three times and reports the following achievements:

- The Board reviewed and revised the educational materials provided by MNHP to families and other stakeholders to reflect best practices in other geographies as well as current resources available to children and their families in Maine.
- The Board reviewed and revised its by-laws/guidelines to clarify roles and responsibilities and streamline processes.
- The Board engaged in educational opportunities to maximize the effectiveness of Board members. These included informational presentations on MNHP as the state EHDI program and its relationship to existing statewide intervention agents, and the certification process for Listening and Spoken Language Specialists.
- The Board initiated a process to incorporate data oriented quality improvement review to identify potential areas of improvement for MNHP.

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 2½ 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 MNHP within the Department of Health and Human Services, Maine Center for Disease Control and Prevention, Division of Population Health.

Funding Sources

MNHP is funded entirely through the Federal U.S. Department of Health and Human Services. The Federal Centers for Disease Control and Prevention awarded MNHP a five-year grant (2011 – 2016) for “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 MNHP a three-year grant (2011 – 2014) to “Reduce the Loss to Follow-up after Failure to Pass Newborn Hearing Screening.”

Personnel

MNHP staffing consists of one full-time Hearing Coordinator and a full-time Office Associate II (currently vacant). Federal grants have allowed MNHP to contract with a full-time Follow-up Coordinator, a part-time Parent Consultant, a part-time Audiologist and support for ChildLINK, a data, tracking, and information system.

Goals, Activities and Achievements

The primary goal of MNHP 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 MNHP 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

MNHP began collaborating with the University of Maine 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. The cooperative agreement for the surveillance and tracking system was extended to December 31, 2012, while the formal Request for Proposals (RFP) process was completed and a new contract awarded. The recipient of the RFP award was the University of Maine and the new contract begins January 1, 2013.

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

Note: 2011 data will be available by February 2013 and will be included in the 2013 Annual Report.

Criteria	Number (%)				
	2006	2007	2008	2009*	2010
Number of Births	14009	13975	13500	13353	12812
Total screened all births	13549 (96.7%)	13602 (97%)	13178 (98%)	13054 (98%)	12502 (98%)
Screened by age 1 month	13189	13560	13060	12812	12304
Not screened	460 (3.3%)	373 (3%)	322 (2%)	299 (2%)	310 (2%)
Infant died or parents declined services	83	97	82	61	81
Missed screening	377	276	240	238	229
Pass screening	13219 (97.6%)	13310 (98%)	12979 (98.5%)	12813 (98%)	12308 (98%)
Refer screening	330 (2.4%)	292 (2%)	199 (1.5%)	241 (2%)	194 (1.6%)
Referred on screening-MNHP received audiological report	112 (33.9%)	146 (50%)	137 (69%)	138 (57%)	131 (68%)
Hearing normal	78	126	93	110	114
Hearing loss	14	20	18	12	17
Diagnosis in progress	20	13	26	16	0
Unknown (LTF)	194 (63.6%)	138 (47%)	62 (30%)	101 (42%)	63 (32%)
Hearing Loss diagnosed, MNHP received confirmation of enrollment with Part C provider-CDS	3	6 (30%)	7 (39%)	3 (25%)	4 (67%)

*MNHP 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

MNHP 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: MNHP 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: MNHP 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. MNHP strives to provide this notebook to every family of every child in Maine who is diagnosed with hearing loss.

Website

www.mainepublichealth.gov/MNHP

Maine CDC Newborn Hearing Program Key Accomplishments in 2012

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 (16%) were screened for hearing loss at birth. To address this disparity, MNHP provided screening equipment and support to a large midwifery practice for screening babies born at home. Preliminary data for 2011 indicates that the screening rate for home births has increased to 21%, representing a 31% improvement over 2010.

Audiology

- Consulted with and provided training and support to several new audiologists to increase awareness of Maine's Pediatric Audiology Guidelines.
- Consulted with Maine audiologists to increase the number of diagnostic reports received by MNHP 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 MNHP'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. The Chapter was awarded one of these grants

and used the funds to assess current knowledge of screening, assessment and early intervention services.

Early Intervention

- Met three times 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.
- Met with the Child Development Services site directors and State staff to present the MNHP early intervention data and to discuss possible ways to improve the data reporting.

Family Support

- Continued to support 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.
- 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. MNHP is waiting for a Request for Proposal to be written and awarded so that Parent Guides can be hired and trained.

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 was initially designed to serve infants with bilateral, severe/profound hearing loss. The majority of children identified by hearing screening have mild/moderate or unilateral hearing losses and have difficulty obtaining needed support and services through Maine's Part C 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.

- Screening rates for home births is low. Screening equipment cannot be used in the home and is cost prohibitive for midwifery practices.
- Lack of information: Many parents are unaware that their babies were screened or are unaware of 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 seven 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 MNHP. This has improved in recent years with the implementation of an online reporting process.
- 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 to access audiologic services.

Risk Factors and Medical Home

- Screeners lack knowledge about the importance of reporting risk factors to MNHP or lack access to this information.
- Primary care providers lack the knowledge on risk factors and the importance and timing of appropriate follow-up.
- Screening sites lack a consistent means of informing families in situations in which infants receive a PASS but require further follow-up due to risk factors. In addition to the PASS, REFER categories; a notification of results that included an additional category of PASS with RISK Factors would reduce this barrier.
- MNHP currently lacks 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

- There is a shortage of qualified service providers.
 - Statewide options are not available to all families in all areas.
 - Families must travel out of state to obtain a cochlear implant.
-

Future Direction

The overall future direction for MNHP 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. To achieve this, MNHP will:

- 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. This is done annually.
- Assure access to early intervention services enrollment data by having MNHP on the Department of Education's Child Development Services Release of Information Form. Ongoing goal from 2011.
- Develop 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.
- Develop quality improvement activities targeted to improve processes and outcomes.