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January 24, 2017

Senator Eric Brakey, Chair
Representative Patricia Hymanson, Chair
Members of the Joint Standing Committee on Health and Human Services
#100 State House Station
Augusta, Maine 04333-0100

Dear Senator Brakey, Representative Hymanson, and Members of the Joint Standing Committee on Health and Human Services:

Enclosed please find the 2016 Annual Report to the Legislature for the Maine Center for Disease Control and Prevention (CDC) Newborn Hearing Advisory Board submitted by the Department of Health and Human Services. This report is required under Title 22 of the M.R.S.A., Chapter 1686, §8821-8825. The report discusses the Maine CDC Newborn Hearing Advisory Board activities in 2016.

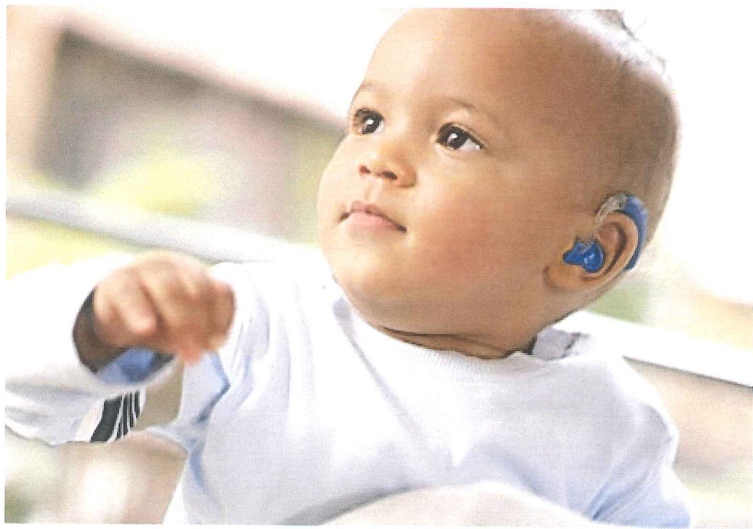
Sincerely,

Mary C. Mayhew
Commissioner

MCM/klv

Enclosure

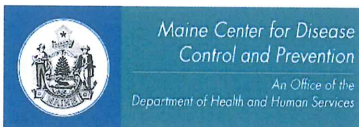
Maine CDC Newborn Hearing Advisory Board



January 1, 2016 - December 31, 2016

Submitted to the Joint Standing
Committee on Health and Human
Services

2016 Annual Report



Paul R. LePage, Governor

Mary C. Mayhew, Commissioner

Table of Contents

Executive Summary	3
Full Report	5
Background	5
Legislation and Rules	5
State Advisory Board	5
Advisory Board Members	6
Program Description	6
Personnel and Funding Sources	6
Goals and Activities	7
Hearing Screen Data	8
Diagnostic Data	9
Early Intervention Data	10
Appendix A	12

EXECUTIVE SUMMARY

December 2016

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 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 statute requires an advisory board for the purpose to provide oversight and advice to the Maine CDC Newborn Hearing Program. Each year the Board is required to report to the Joint Committee on Health and Human Services the percentages of infants screened, evaluated and being offered and receiving early intervention services and treatment.

Highlights

This report uses the 2014 data submitted by Maine CDC Newborn Hearing Program to the U.S. Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Early Hearing Detection and Intervention Program. The 2015 data will be available in March 2017.

Screening

- Ninety-eight percent (12,274) of Maine newborns completed a newborn hearing screen.
- Ninety-eight percent (12,025) of those Maine newborns screened by age 1 month or less “passed”.
- Two percent (220) received a “refer” result for further diagnostic evaluation.
- Two percent (256) of Maine newborns were not screened in 2014; the majority of these unscreened newborns, 57 percent (147), were home births.

Audiological Evaluation

- Seventy-five percent (164) of those infants who received a “refer” result received a completed audiological evaluation.
 - Fifteen percent (25) were identified with a hearing loss and 85 percent (139) were evaluated and were found to have hearing within normal limits.

Early Intervention

- One hundred percent (25) of Maine children with a confirmed hearing loss were referred to Child Development Services (Part-C).
 - The Maine Newborn Hearing Program received information that 52 percent (13) of those confirmed infants were entered into early intervention services.
 - Of those receiving early intervention services, 54 percent (7) of infants with a confirmed hearing loss were receiving early intervention services by 6 months of age.

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

Full Report

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 Program (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 occur no later than 1 month of age, diagnostic audiological evaluations as early as possible, (but no later than 3 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 6 months of age for those identified with hearing loss).

Legislation and Rules

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.

Maine CDC Newborn Hearing Advisory Board

The Maine CDC Newborn Hearing Advisory Board (referred to as 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, an early intervention services provider to children who are deaf or hard of hearing through the Maine Educational Center for the Deaf and Hard of Hearing (MECDHH), 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 a child who is hard-of hearing or deaf, a parent of a hearing child and a representative of each of the following: hospitals, health insurance carriers, early childhood special education program under Title 20-A, Chapter 303, and the Department of Health and Human Services.

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

- Provide oversight and advice to the Maine CDC Newborn Hearing Program;
- Advise the Commissioner of the Department of Health and Human Services on issues relating to the 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 to the Joint Committee on Health and Human Services.

**MNHP Advisory Board Members
January 1, 2016 - December 31, 2016**

Audiologist – Eileen Peterson, M. S. , FAAA	Physician – Duska Thurston, MD
Speech-Language Pathologist – Louise Packness, CCC-SLP	Nurse – Nola Metcalf, RN-C (Co-Chair)
Certified teacher of the deaf – Donna Casavant, MED, CAS	ECFS EI service provider – Karen Hopkins, M. Ed. CAGS
Culturally Deaf person – Catherine Lushman (Co-Chair)	Hard of hearing or deaf person – Romy Spitz, Ph. D.
Parent of a child who is Culturally Deaf – Jennifer Kesaris	Parent of a hard of hearing or deaf child – Tracy LaRue-Hanson
Parent of a hearing child – Sarah Pierce-Bureau	Representative of hospitals – Annette Bowman, RN
Representative of health insurance carriers – Karen Harrison	Representative of Child Development Services (CDS) – Kim Appleby
Representative of DHHS – Christopher Pezzullo, D. O.	Other – Harriet Gray, Ph. D.
Other – vacant	

During the calendar year 2016, The Board met three times and conducted Board business that included discussions on:

- Issues connected with Board vacancies.
- The submission of the USCDC 2014 EHDI data for Maine.
- Committee updates and assignments.
- Provider training on EHDI goals.
- Updating the Program’s website.

On March 29, 2016, The Board held a strategic planning meeting and determined the greatest impact can be made in the areas of provider training and family education. Over the next three years, The Board will focus efforts on training and on the program website.

Program Description

The Maine Newborn Hearing Program was established by law in 2000 to provide information to families about hearing screening, evaluation and available services. The program is also charged with maintaining data as it relates to newborn hearing.

Personnel and Funding Sources

The Maine CDC Newborn Hearing Program (MNHP) is entirely funded through two Federal U.S. Department of Health and Human Services Grants identified below:

- The Federal Centers for Disease Control and Prevention, a five-year, \$150,000/year grant (2011-2016) that funds the following:
 - 50 percent of the State MNHP Coordinator position, which also includes 50 percent of the rent, computer and telephone services and parking expenses.

- A contract with the University of Maine System–Center for Education and Human Development to support the maintenance and enhancement of the Program’s data, tracking and surveillance system called “ChildLINK”.
- Travel to attend the National Early Hearing Detection and Intervention Annual meeting.
- The Maternal and Child Health Bureau/Division of Children with Special Health Needs three-year, \$250,000/year grant (2014-2017) that funds the following:
 - 50 percent of the State MNHP Coordinator position, which also includes 50 percent of the rent, computer and telephone services and parking expenses.
 - A contract with the Maine Education Center for the Deaf and Hard of Hearing for the provision of:
 - Full time follow-up coordinator,
 - Half time parent consultant,
 - Part time pediatric audiologist, and
 - Support for Guide By Your Side - a parent-to-parent program that provides support to families of a newly-diagnosed child who is deaf or hard of hearing by linking with other families and providing resources.
 - A contract with the University of Maine System - Center for Education and Human Development to support the maintenance and enhancement of the Program’s data, tracking and surveillance system called “ChildLINK”.
 - The purchase of pamphlets, brochures and informational packets to support education to various groups including families.

Goals and Activities

The seven national goals for achieving a comprehensive, coordinated, community-based system of services are:

1. **Screening** - All infants will be screened for hearing loss by 1 month of age, preferably before hospital discharge.
2. **Diagnostic Audiology** - All infants who screen positive will have a diagnostic audiological evaluation before 3 months of age.
3. **Early Intervention** - All infants identified with a hearing loss will begin receiving appropriate early intervention services before 6 months of age.
4. **Family Support** - All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.
5. **Medical Home** - All infants with hearing loss will have a medical home.
6. **Data Management** – Each state will develop a tracking and surveillance system that ensures that babies referred from the screening receive appropriate and timely diagnostic audiological and early intervention services.
7. **Evaluation** – Each state will develop an evaluation plan that improves the overall effectiveness of the service delivery system and meets the needs of families.

This report uses 2014 data submitted by the Maine CDC Newborn Hearing Program to the U.S. Centers for Disease Control and Prevention, National Birth Defects Prevention and Developmental Disabilities, Early Hearing Detection and Intervention Program to describe

screening, evaluation, early intervention services and the demographic characteristics of the population. The 2015 screening data will be available in March 2017.

Hearing Screen Data

The primary goal of the Maine Newborn Hearing Program is to ensure that every child born in Maine is screened for hearing loss and that those with a confirmed hearing loss are referred to Child Development Services for early intervention services. *Healthy People 2020* set the benchmark for screening no later than age one month at 90.2 percent. Maine continues to exceed the goal with a screening rate of 98 percent.

Objective: Increase the proportion of newborns who are screened for hearing loss no later than age 1 month

Baseline: 82.0 percent of Maine newborns aged one month or less had screening for hearing loss in 2007.

Target: 90.2 percent

Achieved: 98.0 percent 2014

In 2014, the Maine CDC Data, Research and Vital Statistics reported that there were a total of 12,530 births in Maine. The total number of infants screened was 12,274 (98%). The percentage of Maine newborns that “passed” a screening by one month of age was 98% or 12,025 infants. A total of 220 infants (2%) did “not pass” the initial screen and any subsequent rescreening and were subsequently “referred”.

Table 1: Number of Infants Not Screened in 2014

Infants not Screened					
Total not screened	Infant died	Parents declined screening	Moved out of state/non-resident	Transferred out-of-state	Missed
283 (2 percent)	61	30	7	2	156
Data Source: CDC/NCBDDD/EHDI 2014					

Further analysis of the 156 infants who “missed” the newborn hearing screen reveals the following: 147 were home births; two had full diagnostic testing done by an audiologist, seven were unable to be screened prior to hospital discharge due to broken equipment. Of the seven not screened due to equipment issues, two had full diagnostic testing done by an audiologist, four families did not return for scheduled follow-up and stated that they felt the screening was unnecessary, and one family was unable to be contacted.

Advisory Board Recommendations

- Continue to educate hospital administrators, nurse managers and other stakeholders to maintain the current screening rate of 98 percent.
- Partner with the Maine Association of Certified Professional Midwives (MACPM) to improve the system for screening infants when they are born outside of the hospital system.

- Explore the purchase of several portable screeners for MACPM personnel to expand access to screening for families who choose to deliver at home.
- Work with Birthwise Midwifery School to present information to students on the importance of newborn hearing screening.

Diagnostic Data

According to the National Center for Hearing Assessment and Management (NCHAM), if a baby does not pass the initial newborn hearing screening, the next step in the process is the diagnostic evaluation. The objective is to have the diagnostic tests completed as soon as possible, preferably before three months of age. The diagnostic evaluation should be performed by a pediatric audiologist with expertise working with infants and children.

Healthy People 2020 has established the following objective related to newborns receiving an audiological evaluation after a “refer” at screening.

Objective: Increase the proportion of newborns who receive audiological evaluation no later than age 3 months for infants who did not pass the hearing screening.

Baseline: 66.0 percent of Maine infants aged three months and under who did not pass the hearing screening received audiological evaluation in 2007.

Target: 72.6 percent

Achieved: 75 percent in 2014

As reported above, the percentage of newborns who were “referred” after the initial screen and any subsequent rescreening was 2 percent or 220 infants. Seventy-five percent (164) of infants who referred on their hearing screen received a diagnostic evaluation and the program received a report. Seventy-one percent (116) of those children received a diagnostic evaluation no later than three months of age.

Table 2: The percent and number of infants who received an audiological (diagnostic) evaluation during 2014

Diagnostic Evaluation			
Total not pass “refer”	Total infants with normal hearing	Total infants diagnosed with hearing loss	Total infants with no diagnosis
220	139 (85%)	25 (15%)	56 (25%)
Data Source: CDC/NCBDDD/EHDI 2014			

Further analysis of the 56 newborns with no diagnosis reveals the following: one child died, nine families moved out of state; seven families declined any further services; 31 families were unresponsive to multiple attempts at contact; MNHP was unable to contact four families because of missing or incorrect contact information and the Primary Care Provider (PCP) was unknown; four children were seen by an audiologist, but the testing was incomplete.

A total of 56 children were identified with a confirmed hearing loss. Twenty-five of these children referred on their newborn hearing screen. Thirty-one of these children either did not

have a hearing screen or passed their newborn hearing screen and were later confirmed to have a hearing loss (late-onset, acquired, or progressive hearing loss).

Advisory Board Recommendations

- Work with audiologists to encourage the use of the on-line reporting form.
- Educate and encourage all birthing centers to make audiological referrals for infants who do not pass their newborn hearing screen.
- Monitor audiological referrals/FAXs from birthing facilities via ChildLINK.
- Request newborn screening policies from hospitals to ensure that the policy includes making referrals to audiologists prior to discharge for infants who do not pass their newborn hearing screen.
- Work with hospitals and ChildLINK to improve timeliness of reported equipment failures and data errors.
- Survey hospitals to determine barriers that prohibit them from scheduling audiological appointments and notifying the MNHP and the child's PCP.
- ChildLINK should automatically notify the EHDI Coordinator when an audiology report is received.
- Review "at risk" children and recommend follow-up diagnostic evaluations.
- Collaborate with the other New England states to develop a quality improvement project that improves early access to border babies thereby decreasing "Lost to Follow-up/Diagnosis" (LFU/D).
- Encourage audiologists to register with the EHDI-PALS (Pediatric Audiology Links to Services) website.

Early Intervention Data

Healthy People 2020 has established the following objective related to infants who are enrolled in early intervention services.

Objective: Increase the proportion of infants with confirmed hearing loss who are enrolled for intervention services no later than age 6 months.

Baseline: 50.0 percent of Maine infants aged 6 months and under with confirmed hearing loss were enrolled for intervention service in 2007.

Target: 55.0 percent

Achieved: 52.0 percent for 2014

There were a total of 25 infants diagnosed with hearing loss who did not pass their newborn hearing screen. All 25 (100 percent) were referred to Child Development Services (CDS), Part C Early Intervention (EI) Services. The Maine Newborn Hearing Program received confirmation that 13 children were receiving early intervention services from Child Development Services. The Maine CDC Newborn Hearing Program can confirm that one family declined any further services, one child was found ineligible for services, two families were unable to be contacted by either the Program or Child Development Services. The Program was unable to confirm that the remaining eight children were receiving early intervention services due to the Family Education and Privacy Rights (FERPA) Law. FERPA is the federal law that protects student privacy by prohibiting access to records without written consent of a parent or guardian.

Table 3: Percent and number of children enrolled in Part C early intervention services.

Total children enrolled in Part C		
	Total enrolled	Total enrolled before 6 months of age
Part-C	13 (52%)	7 (54 %)
Data Source: CDC/NCBDDD/EHDI 2014		

Individuals with Disabilities Act (IDEA): Part C - early intervention program for infants and toddlers provides a broad array of services to children with special health needs and developmental disabilities, age birth through 3 years of age. In Maine, Child Development Services is responsible for the Part C services.

Advisory Board Recommendations

- Work with Child Development Services and Maine Educational Center for the Deaf and Hard of Hearing/Early Child and Family Services to ensure that MNHP is included on the release of information request form.

Appendix A
2014 Early Hearing Detection and Intervention Data
January 1, 2014 – December 31, 2014

2014 EHDI Data-Maine
(Final as of 5-6-16)

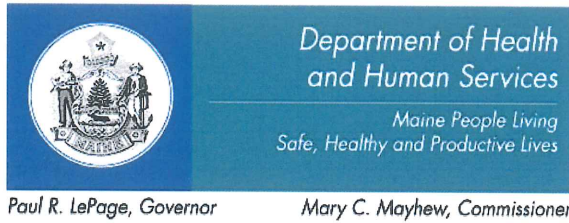
Shaded areas provide further detail on the babies reported as not screened, no diagnosis,
unknown and early intervention

Criteria	Number	Percentage (%)
Number of Births	12,530	
Hospital births	12,296	
Non-hospital births	234	
SCREENING DATA		
Screened	12,274	98
Screen complete by 1 month	12,025	98
Hospital births screened	12,192	99
Home birth screened	73	31
Not screened	256	2
Infant died	61	
Parents declined services	30	
Moved out of state/non-resident	7	
Infant transferred no documentation of screen	2	
Missed screening	156	
Missed-home birth	147	
Missed-hospital birth, had full diagnostics	2	
Missed-equipment issues (broken or missing supplies)	7	
Equip. issue-went for full diagnostics	2	
Equip. issue-unable to contact	1	
Equip. issue-did not return for scheduled follow-up-stated it was unnecessary	4	
Pass screening	12,054	98
Not pass screening	220	2

DIAGNOSTIC DATA		
Not pass screening-MNHP received audiological report w/diagnosis complete	164	75
Diagnosis complete by 3 months	116	71
Hearing normal	139	
Hearing loss	25	
Total-no diagnosis received	56	
Infant died	1	
Moved out of state	9	
Family declined follow-up	7	
Family unresponsive	31	
Lost to documentation/follow-up	8	4
Unable to contact parent & PCP unknown	4	
'unknown' (per USCDC definition) all went to aud. but did not have complete testing	4	

EARLY INTERVENTION DATA		
Refer NHS, Hearing Loss-MNHP received confirmation of enrollment with Part C Provider-CDS	13	52
Referred to EI by 6 months of age (10 of the 25 were diagnosed after 6 months of age)	13	
Enrolled in EI by 6 months	7	54
Family declined EI	1	
Family unresponsive	2	
Ineligible	1	
Lost to documentation/follow-up	8	32
Unable to contact	1	
Likely enrolled with EI-GBYS received request for services-MNHP did not receive info from EI	3	
Unknown	4	

LATE-ONSET, PROGRESSIVE, ACQUIRED HEARING LOSS		
Passed/missed screening-MNHP received report of hearing loss (i. e. late-onset, etc.)	31	
Late onset, etc. HL report received, confirmation of enrollment with Part C	1	
Hearing loss ID before 6 months of age	1	
Average age of diagnosis	16 months (range 4 to 27 mos)	



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