

Maine CDC Newborn Hearing Advisory Board



January 1, 2017 - December 31, 2017

Submitted to the Joint Standing
Committee on Health and Human
Services

2017 Annual Report



Paul R. LePage, Governor

Ricker Hamilton, 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	8
Early Intervention Data	9
Appendix A	11

EXECUTIVE SUMMARY

December 2017

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 2015 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 2016 data will be available in April 2018.

Screening

1. Ninety-eight percent (12,093) of Maine newborns completed a newborn hearing screen.
2. Ninety-nine percent (11,913) of those Maine newborns screened “passed” the screening.
3. One percent (180) received a “refer” result for further diagnostic evaluation.
4. Two percent (279) of Maine newborns were not screened in 2015; the majority of these unscreened newborns, 68 percent (191), were home births.

Audiological Evaluation

5. Seventy-five percent (135) of those infants who received a “refer” result received a completed audiological evaluation.
 - Twenty-three percent (31) were identified with a hearing loss and 77 percent (104) were evaluated and were found to have hearing within normal limits.

Early Intervention

6. One hundred percent (31) of Maine children with a confirmed hearing loss were referred to Child Development Services (Part-C).
 - The Maine Newborn Hearing Program received information that 42 percent (13) of those confirmed infants were entered into early intervention services.
 - Of those receiving early intervention services, 69 percent (9) of infants with a confirmed hearing loss were receiving early intervention services by six 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 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

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
December 31, 2017**

Audiologist – Eileen Peterson, M. S. , FAAA	Physician – Duska Thurston, MD (Co-chair)
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	Hard of hearing or deaf person – vacant
Parent of a child who is Culturally Deaf – Jennifer Kesaris	Parent of a hard of hearing or deaf child – Amber Woodcock
Parent of a hearing child – Sarah Pierce-Bureau	Representative of hospitals – Annette Bowman, RN
Representative of health insurance carriers – vacant	Representative of Child Development Services (CDS) – vacant
Representative of DHHS – Christopher Pezzullo, D. O.	Other – Harriet Gray, Ph. D.
Other – Susan Delaney, CPM	

During the calendar year 2017, The Board met two times and conducted Board business that included discussions on:

- Issues connected with Board vacancies
- The submission of the USCDC 2015 EHDI data for Maine
- Committee updates and assignments
- Provider training on EHDI goals
- Updating the Program’s 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 funded through three Federal U.S. Department of Health and Human Services Grants and one dedicated revenue account identified below:

1. The Federal Centers for Disease Control and Prevention, a five-year, \$150,000/year grant (2017-2022) 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 Grantee annual meeting.
2. The Maternal and Child Health Block Grant through the Health Resources and Services Administration (HRSA) that funds the following:
 - Fifty percent of the State MNHP Coordinator position, which also includes 50 percent of the rent, computer and telephone services and parking expenses.
 3. HRSA Grant Funds, three year 2014-2017 (ended March 31, 2017) that funded the following:
 - This grant was used to improve the screening to intervention system to reduce the number of infants who are lost to follow-up, diagnosis and intervention.
 4. A dedicated revenue account through Children with Special Health Needs
 - A contract with the Maine Educational 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

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 one month of age, preferably before hospital discharge.
2. **Diagnostic Audiology** - All infants who screen positive will have a diagnostic audiological evaluation before three months of age.
3. **Early Intervention** - All infants identified with a hearing loss will begin receiving appropriate early intervention services before six 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 2015 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 (CDC/NCBDDD/EHDI) to describe screening, evaluation, early intervention services and the demographic characteristics of the population. The 2016 screening data will be available in April 2018.

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 one month

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

Target: 90.2%

Achieved: 98.0% 2015

In 2015, the Maine CDC Data, Research and Vital Statistics reported that there were a total of 12,372 births in Maine. The total number of infants screened was 12,093 (98%). The percentage of Maine newborns that “passed” a screening was 99% or 11,913 infants. A total of 180 infants (1%) did “not pass” the initial screen and any subsequent rescreening and were subsequently “referred”.

Table 1: Number of Infants Not Screened in 2015

Infants not Screened					
Total not screened	Infant died	Parents declined screening	Moved out of state/non-resident	Transferred out-of-state	Missed
279 (2 %)	52	26	2	2	197
Data Source: CDC/NCBDDD/EHDI 2015					

Further analysis of the 197 infants who “missed” the newborn hearing screen reveals the following: 191 were home births; two had full diagnostic testing done by an audiologist, one missed hospital screening prior to discharge and the family was unresponsive to attempts to get the child screened, three were unable to be screened prior to hospital due to other medical issues. The three not screened due to other medical issues had full diagnostic testing done by an audiologist.

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 three months for infants who did not pass the hearing screening.

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

Target: 72.6%

Achieved: 75% in 2015

As reported above, the percentage of newborns who were “referred” after the initial screen and any subsequent rescreening was 1 percent or 180 infants. Seventy-five percent (135) of infants who referred on their hearing screen received a diagnostic evaluation and the program received a report. Sixty-six percent (89) 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 2015

Diagnostic Evaluation			
Total not pass “refer”	Total infants with normal hearing	Total infants diagnosed with hearing loss	Total infants with no diagnosis
180	104 (77%)	31 (23%)	45 (25%)
Data Source: CDC/NCBDDD/EHDI 2015			

Further analysis of the 45 newborns with no diagnosis reveals the following: four children died, five families moved out of state; ten families declined any further services; 20 families were unresponsive to multiple attempts at contact; four children were seen by an audiologist, but the testing was incomplete.

A total of 56 children were identified with a confirmed hearing loss. Thirty-one of these children referred on their newborn hearing screen. Twenty-five 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).

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 six months.

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

Target: 55.0%

Achieved: 42.0% for 2015

There were a total of 31 infants diagnosed with hearing loss who did not pass their newborn hearing screen. All 31 (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 three families declined any further services, one family was unable to be contacted by either the Program or Child Development Services. The Program was unable to confirm that the remaining fourteen 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 (42%)	9 (69%)
Data Source: CDC/NCBDDD/EHDI 2015		

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, birth through three years of age. In Maine, Child Development Services is responsible for the Part C services.

Appendix A

**2015 Early Hearing Detection and Intervention Data
January 1, 2015 – December 31, 2015**

**2015 EHDI Data-Maine
(Final as of 9-19-17)**

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

Criteria	Number	Percentage (%)
Number of Births	12372	
Hospital births	12106	98%
Non-hospital births	266	2%
SCREENING DATA		
Screened	12093	98%
Hospital births screened	12019	99%
Home birth screened	74	28%
Screen complete by 1 month	11806	98%
Not screened	279	2%
Infant died	52	
Parents declined services	26	
Non-resident	2	
Infant transferred out of state, no documentation of screen	2	
Missed screening	197	2%
Missed-home birth	191	
Missed-hospital birth, had full diagnostics	2	
Missed-unresponsive	1	
Missed-medically unable to screen (all went for full diagnostics)	3	
Pass screening	11913	99%
Not pass screening	180	1%
DIAGNOSTIC DATA		
Not pass screening-MNHP received audiological report w/diagnosis complete	135	75%
Diagnosis complete by 3 months	89	66%
Hearing normal	104	
Hearing loss	31	
Total-no diagnosis received	45	
Infant died	4	
Moved out of state	5	

Family declined follow-up	10	
Family contacted but unresponsive	20	
Lost to documentation/follow-up	4	2%
'other' (per USCDC definition) all went to aud. but did not have complete testing	4	

EARLY INTERVENTION DATA		
Refer NHS, Hearing Loss, referred to Part C providerCDS	31	100%
Refer NHS, Hearing Loss-MNHP received confirmation of enrollment with Part C Provider-CDS	13	42%
Referred to EI by 6 months of age (12 of the 31 were diagnosed after 6 months of age)	15	
Enrolled in EI by 6 months	9	69%
Family declined EI	3	
Lost to documentation/follow-up	15	48%
Unable to contact	1	
Unknown	14	
LATE-ONSET, PROGRESSIVE, ACQUIRED HEARING LOSS		
Passed/missed screening-MNHP received report of hearing loss (i.e. late-onset, etc)	25	
Referred to Part C provider-CDS	25	100%
Late onset, etc. HL report received, confirmation of enrollment with Part C	3	12%
Hearing loss ID before 6 months of age	4	16%
Average age of diagnosis	17 months (range 3 to 30 mos)	



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