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Maine CDC Newborn Hearing Advisory Board



January 1, 2018 - December 31, 2018



Submitted to the Joint Standing
Committee on Health and Human
Services by the Department of
Health and Human Services

2018 Annual Report

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EXECUTIVE SUMMARY

December 2018

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

Highlights

This report uses the 2016 data submitted by the MNHP 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 2017 data will be available in April 2019.

Screening (Total number of births 12,480)

1. Ninety-eight percent (12,192) of Maine newborns completed a newborn hearing screen.
2. Ninety-nine percent (12,112) of those Maine newborns screened “passed” the screening.
3. One percent (151) received a “refer” result for further diagnostic evaluation.
4. Two percent (288) of Maine newborns were not screened in 2016; the majority of these unscreened newborns, 69 percent (200), were home births.

Audiological Evaluation

5. Seventy-seven percent (116) of those infants who received a “refer” result received a completed audiological evaluation.
 - Eleven percent (13) were identified with a hearing loss and 89 percent (103) were evaluated and were found to have hearing within normal limits.

Early Intervention

6. One hundred percent (13) of Maine children with a confirmed hearing loss were referred to Child Development Services (Part-C).
 - The MNHP received information that 77 percent (10) of those confirmed infants were entered into early intervention services.
 - Of those receiving early intervention services, 70 percent (7) of infants with a confirmed hearing loss were receiving early intervention services by six months of age.

For more information on the MNHP: Contact Holly Richards, Program Manager for Newborn Bloodspot, Genetics and Hearing Program, holly.richards@maine.gov or 207-287-4623
www.mainepublichealth.gov/MNHP

Full Report

Background

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 Newborn Hearing Program (MNHP), which functions to support the early identification and timely and appropriate intervention for hearing loss. 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 Newborn Hearing Advisory Board

The Maine 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 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, 2018**

Audiologist – Eileen Peterson, M. S. , FAAA	Physician – Duska Thurston, MD (Co-chair)
Speech-Language Pathologist – Louise Packness, CCC-SLP	Nurse – Nola Metcalf, RN-C (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 – Harriet Gray, ph.D
Parent of a child who is Culturally Deaf – Jennifer Gaulin	Parent of a hard of hearing or deaf child – Vacant
Parent of a hearing child – Vacant	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 – Susan Delaney, CPM

During the calendar year 2018, The Board met three times and conducted Board business that included discussions on:

- Powerpoint training for providers
- Updating the Program’s website
- Updating the Program’s rules
- Issues connected with Board vacancies
- The submission of the USCDC EHDI data for Maine
- Updating the Board’s mission, by-laws, and orientation guide

Program Description

The MNHP 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 MNHP is funded through two 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 three-year, \$150,000/year grant (2017-2020) 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.
 - 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:
 - o Fifty percent of the State MNHP Coordinator position, which also includes 50 percent of the rent, computer and telephone services and parking expenses.
 - o 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 2016 data submitted by the MNHP 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 2017 screening data will be available in April 2019.

Hearing Screen Data

The primary goal of the MNHP 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% 2016

In 2016, the Maine CDC Data, Research and Vital Statistics reported that there were a total of 12,480 births in Maine. The total number of infants screened was 12,192 (98%). The percentage of Maine

newborns that “passed” a screening was 99 percent or 12,112 infants. A total of 151 infants (1%) did “not pass” the initial screen and any subsequent rescreening and were subsequently “referred”.

Table 1: Number of Infants Not Screened in 2016

Infants not Screened					
Total not screened	Infant died	Parents declined screening	Moved out of state/non-resident	Transferred out-of-state	Missed
288 (2%)	53	19	11	2	203
Data Source: CDC/NCBDDD/EHDI 2016					

Further analysis of the 203 infants who “missed” the newborn hearing screen reveals the following: 200 were home births; one was adopted; one missed hospital screening prior to discharge but ended up getting full diagnostic testing and one unable to be screened prior to hospital due to other medical issues.

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: 77% in 2016

As reported above, the percentage of newborns who were “referred” after the initial screen and any subsequent rescreening was 1 percent or 151 infants. Seventy-seven percent (116) of infants who referred on their hearing screen received a diagnostic evaluation and the program received a report. Sixty-three percent (73) 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 2016

Diagnostic Evaluation			
Total not pass “refer”	Total infants with normal hearing	Total infants diagnosed with hearing loss	Total infants with no diagnosis
116	103 (89%)	13 (11%)	35 (30%)
Data Source: CDC/NCBDDD/EHDI 2016			

Further analysis of the 35 newborns with no diagnosis reveals the following: two children were non-residents, one moved out of state, one was unable to be tested due to medical reasons, one was adopted, seven families declined follow up and twenty-three families were unresponsive to multiple attempts at contact.

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: 77% for 2016

There were a total of 13 infants diagnosed with hearing loss who did not pass their newborn hearing screen. All 13 (100%) were referred to CDS, Part C Early Intervention (EI) Services. The MNHP received confirmation that 10 children were receiving early intervention services from CDS. The MNHP can confirm that two families declined any further services and one family was ineligible for Part C CDS Services.

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	10 (77%)	7 (70%)
Data Source: CDC/NCBDDD/EHDI 2016		

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

2016 Early Hearing Detection and Intervention Data January 1, 2016 – December 31, 2016

2016 EHDI Data-Maine

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	12,480	
Hospital births	12,197	98%
Non-hospital births	283	2%
SCREENING DATA		
Screened	12,192	98%
Hospital births screened	12,112	99%
Home birth screened	80	28%
Screen complete by 1 month	11,920	98%
Not screened	288	2%
Infant died	53	
Parents declined services	19	
Non-resident	11	
Infant transferred out of state, no documentation of screen	2	
Missed screening	203	2%
Missed-home birth	200	
Missed-hospital birth, had full diagnostics	1	
Missed-unresponsive	1	
Missed-medically unable to screen (all went for full diagnostics)	1	
Pass screening	12,041	99%
Not pass screening	151	1%
DIAGNOSTIC DATA		
Not pass screening-MNHP received audiological report w/diagnosis complete	116	77%
Diagnosis complete by 3 months	73	63%
Hearing normal	103	
Hearing loss	13	
Total-no diagnosis received	35	
Non-resident	2	
Moved out of state	1	
Unable to test due to medical reasons	1	
Adopted	1	
Family declined follow-up	7	
Lost to documentation/follow-up	23	15%
Family contacted but unresponsive	18	

Unable to contact	1	
Unknown	4	
Tests done out of state; unable to get results	2	
Went to audiologist but did not have complete testing	2	

EARLY INTERVENTION DATA		
Refer NHS, Hearing Loss, referred to Part C provider-CDS	13	100%
Refer NHS, Hearing Loss-MNHP received confirmation of enrollment with Part C Provider-CDS	10	77%
Documentation of IFSP date received	7	100%
Enrolled in EI by 6 months	7	70%
Enrolled in EI by 6 months	3	
Family declined EI	2	
Ineligible for Part C Services	1	
Lost to documentation/follow-up	0	
Unable to contact	0	
Unknown	0	
LATE-ONSET, PROGRESSIVE, ACQUIRED HEARING LOSS		
Passed/missed screening-MNHP received report of hearing loss (i.e. late-onset, etc)	20	
Referred to Part C provider-CDS	10	
Late onset, etc. HL report received, confirmation of enrollment with Part C	4	
Hearing loss ID before 6 months of age	6	16%
Average age of diagnosis	8.9 months (range 1.5 to 19.9 months)	



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