Janet T. Mills
Governor

Jeanne M. Lambrew, Ph.D.
Commissioner

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January 13, 2020

Senator Geoff Gratwick, Chair
Representative Patricia Hymanson, Chair
Joint Standing Committee on Health and Human Services
100 State House Station
Augusta, Maine 04333-0100

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

Enclosed please find the 2019 Annual Report to the Legislature by the Maine Center for Disease Control and Prevention's Newborn Hearing Advisory Board. The Department of Health and Human Services submits the report as required under Title 22 of the M.R.S.A., Chapter 1686. It discusses the percentages of children being screened and evaluated, and those children being offered and receiving intervention and treatment services in 2019.

Of note, since this report was developed, two additional members have been appointed to the Board, including a representative of the Department of Health and Human Services and a representative of a Hospital.

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 Advisory Board.

Sincerely,

Jeanne M. Lambrew

Jeanne M. Lambrew, Ph.D.
Commissioner

JML/klv

Enclosure

Maine CDC Newborn Hearing Advisory Board

January 1, 2019 - December 31, 2019

Submitted to the Joint Standing
Committee on Health and Human
Services

2019 Annual Report

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EXECUTIVE SUMMARY
December 2019

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 to provide oversight and advice to the Maine CDC Newborn Hearing Program. 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 2017 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 2018 data will be available in April 2020.

Screening (Total number of births 12,075)

1. Ninety-eight percent (11,789) of Maine newborns completed a newborn hearing screen.
2. Ninety-eight percent (11,558) of those Maine newborns screened "passed" the screening.
3. Two percent (231) received a "refer" result for further diagnostic evaluation.
4. Two percent (288) of Maine newborns were not screened in 2017; the majority of these unscreened newborns, 69 percent (197), were home births.

Audiological Evaluation

5. Seventy-eight percent (180) of those infants who received a "refer" result received a completed audiological evaluation.
    - Twelve percent (21) were identified with a hearing loss and 88 percent (159) were evaluated and were found to have hearing within normal limits.

Early Intervention

6. One hundred percent (21) of Maine children with a confirmed hearing loss were referred to Child Development Services (Part-C).
    - The Maine Newborn Hearing Program received information that 67 percent (14) of those infants were entered into early intervention services.
    - Of those receiving early intervention services, 64 percent (9) of infants with a confirmed hearing loss were receiving early intervention services by six months of age.

For more information on the MNHP: *Contact Anne Banger, Newborn Hearing Program Coordinator, Genetics and Hearing Program,* anne.banger@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 that hearing screening for all newborns occurs no later than at one month of age. It also aims to ensure 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 deaf people, 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.
- Submit an annual report on the percentages of children being screened and evaluated, as well as 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, 2019

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 –** Laura Sweet
Parent of a hearing child – Vacant	**Representative of hospitals –** Vacant
Representative of health insurance carriers Vacant	**Representative of Child Development Services (CDS) –** Melinda Corey, M.Ed
Representative of DHHS – Vacant	**Other –** Susan Delaney, CPM
Other – Katherine Duncan, Au.D.	

During calendar year 2019, the Board met three times and conducted business that included discussions on:

- 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, bylaws, and orientation guide.

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 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. A contract with Nebulogic to develop an updated tracking and surveillance system went live October 1, 2019.

  - 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.
   - A contract with the Maine Educational Center for the Deaf and Hard of Hearing (which ceased June 30, 2019) for the provision of a:
     - 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 2017 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 2018 screening data will be available in April 2020.

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: 95.5% 2017

In 2017, the Maine CDC Data, Research and Vital Statistics reported that there were a total of 12,075 births in Maine. The total number of infants screened was 11,789 (98%). The percentage of Maine newborns who "passed" a screening was 98 percent or 11,558 infants. A total of 231 infants (2%) did "not pass" the initial screen and any subsequent rescreening and were subsequently "referred".

Table 1: Number of Infants Not Screened in 2017

Infants not Screened					
Total not screened	**Infant died**	**Parents declined screening**	**Moved out of state/non-resident**	**Transferred out-of-state**	**Missed**
286 (2%)	58	18	5	3	202
Data Source: CDC/NCBDDD/EHDI 2017					

Further analysis of the 202 infants who "missed" the newborn hearing screen reveals the following: 197 were home births; and five missed hospital screening prior to discharge, but ended up getting full diagnostic testing.

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: 78.0% in 2017

As reported above, the percentage of newborns who were "referred" after the initial screen and any subsequent rescreening was 2 percent or 231 infants. Seventy-eight percent (180) of infants who were referred on their hearing screen received a diagnostic evaluation and the program received a report. Fifty-seven percent (132) of those children received a diagnostic evaluation no later than three months of age.

Table 2: The percentage and number of infants who received an audiological (diagnostic) evaluation during 2017

Diagnostic Evaluation			
Total not pass "refer"	**Total infants with normal hearing**	**Total infants diagnosed with hearing loss**	**Total infants with no diagnosis**
231	159 (69%)	21 (9%)	51 (22%)
Data Source: CDC/NCBDDD/EHDI 2017			

Further analysis of the 51 newborns with no diagnosis reveals the following: one child audiological diagnosis is in process, one child was non-resident, one was unable to be tested due to medical reasons, one was not tested due to cost of testing, six children had testing but not best practice testing, thirteen families declined follow-up, twenty-six families were unresponsive to multiple attempts at contact and two families could not be contacted.

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: 67.0% for 2017

There were a total of 21 infants diagnosed with hearing loss who did not pass their newborn hearing screen. All 21 (100%) were referred to Child Development Services (CDS), Part C Early Intervention (EI) Services. The Maine Newborn Hearing Program received confirmation that 14 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 and two families were contacted by Part C CDS but were unresponsive.

Table 3: Percentage 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	14 (67%)	9 (64%)
Data Source: CDC/NCBDDD/EHDI 2017		

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

2017 Early Hearing Detection and Intervention Data
January 1, 2017 – December 31, 2017

2017 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	**12,075**	
Hospital births	11,811	98%
Non-hospital births	264	2%
SCREENING DATA		
Screened	**11,789**	**98%**
Hospital births screened	11,722	99%
Home birth screened	67	25%
Screen complete by 1 month	11,534	98%
Not screened	**286**	**2%**
Infant died	58	
Parents declined services	18	
Non-resident	5	
Infant transferred out of state, no documentation of screen	3	
Missed screening	202	2%
Missed-home birth	197	
Missed-hospital birth, had full diagnostics	4	
Missed-unresponsive	0	
Missed-medically unable to screen (all went for full diagnostics)	1	
Pass screening	**11,558**	**98%**
Not pass screening	**231**	**2%**
DIAGNOSTIC DATA		
Not pass screening-MNHP received audiological report w/diagnosis complete	**180**	**78%**
Diagnosis complete by 3 months	132	73%
Hearing normal	159	
Hearing loss	21	
Total-no diagnosis received	**51**	
Non-resident	1	
Moved out of state	0	
Unable to test due to medical reasons	1	
Audiological Diagnosis in Process	1	
Family declined follow-up	13	

Lost to documentation/follow-up	**35**	**15%**
Family contacted but unresponsive	26	
Unable to contact	2	
Cost of Testing	1	
Tests done out of state; unable to get results	0	
Went to audiologist but did not have complete testing	6	

EARLY INTERVENTION DATA		
Refer NHS, Hearing Loss, referred to Part C provider-CDS	**21**	**100%**
Refer NHS, Hearing Loss-MNHP received confirmation of enrollment with Part C Provider-CDS	**14**	**67%**
Documentation of IFSP date received	14	100%
Enrolled in EI by 6 months	**9**	**64%**
Family contacted but unresponsive	2	
Family declined EI	1	
Ineligible for Part C Services	0	
Lost to documentation/follow-up	**4**	**5%**
Unable to contact	0	
Unknown	4	

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