Maine CDC Newborn Hearing Advisory Board

2022 Annual Report

January 1, 2022 – December 31, 2022

Submitted to the Joint Standing Committee on
Health and Human Services

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EXECUTIVE SUMMARY

Background

The 119th Maine State Legislature passed Public Law 1999, c. 647, adopted under the authority of 22 MSR c. 1686, §§ 8821-8825 establishing the Maine's Newborn Hearing Program within the Department of Health and Human Services – Maine Center for Disease Control and Prevention (Maine CDC). 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 Newborn Hearing Advisory 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 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 (US CDC EHDI Program). Data reflects hearing screening and related services for babies born in 2020.

Screening (Total number of births 11,300)

1. Ninety-seven percent (10,939) of Maine newborns completed a newborn hearing screen.
2. Three percent (361) of Maine newborns were not screened in 2020; the majority of these unscreened newborns, 91 percent (210), were home births.
3. Ninety-seven percent (10,610) of those Maine newborns screened "passed" the screening.
4. Three percent (329) received a "refer" result for further audiological evaluation.

Audiological Evaluation

5. Seventy-nine percent (261) of those infants who received a "refer" result received a completed audiological evaluation.
    - Eleven percent (29) were identified with a hearing loss and 89 percent (232) were found to have hearing within normal limits.

Early Intervention

6. One hundred percent (29) of Maine children with a confirmed hearing loss were referred to Child Development Services (Part-C).
    - The Maine CDC Newborn Hearing Program received information that 69 percent (20) of those infants were entered into early intervention services.
    - Of those receiving early intervention services, 65 percent (13) 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 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 and no later than six months of age for those identified with hearing loss.

Legislation and Rules

Maine's Newborn Hearing Advisory Board (the 'Board') was created by the 119th Maine State Legislature through the enactment of Public Law 1999, c 647 to provide oversight and oversee the program and make recommendations for hearing screening, evaluation, intervention services. Under the authority of 22 MRS§ 8825, the Maine CDC administers program rules (10-144 CMR chapter 279) governing the responsibilities of hospital administration and staff, primary healthcare providers, the Maine Newborn Hearing Program, pediatric audiologic providers and others, with regard to the screening of newborn infants for hearing loss and the tracking and follow-up of identified infants and children up to 3 years of age who are deaf or hard-of-hearing.

Maine CDC Newborn Hearing Advisory Board

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,
- 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 child without hearing loss,
- A representative from hospitals,
- A representative of health insurance carriers, and
- A representative from an early childhood special education program under 20-A MRS, chapter 303, and the Department of Health and Human Services (the 'Department').

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 Maine CDC Newborn Hearing 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.

The Maine CDC Newborn Hearing Advisory Board Members

December 31, 2022

Audiologist – Nicole Duncan	**Physician –** Duska Thurston, MD
Speech-Language Pathologist – Amy Spencer, MS	**Nurse –** Vacant
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) –** Ariana Whiting, LMSW-cc
Representative of DHHS – Stephanie Lavigne	**Other –** Susan Delaney, CPM, (Co-chair)
Other – Katherine Duncan, Au.D. (Chair)	

During calendar year 2022, the Board met three times virtually due to coronavirus restrictions and conducted business that included discussions on:

- Updating the Maine CDC Newborn Hearing Program's website
- Updating the Maine CDC Newborn Hearing Program's rules
- Issues connected with vacancies on the Board
- The submission of the US CDC EHDI data for Maine[1]
- Reviewing and updating the Maine CDC Newborn Hearing Program publications and brochures
- Screening home birth babies
- COVID-19 impacts

The Maine Newborn Hearing Program Coordinator will assist members of the public interested in attending scheduled board meetings.

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[1] US CDC Early Hearing Detection and Intervention Program website: https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

Program Description

The Maine Newborn Hearing Program provides information to providers and families about hearing screening, evaluation, and available services. Hospital and birth facilities report all data on hearing screening, evaluation and diagnoses of newborn infants and children up to 3 years of age to the Maine CDC Newborn Hearing Program charged with maintaining data as it relates to newborn hearing.

Personnel and Funding Sources

The Maine CDC Newborn Hearing Program is funded through two federal U.S. Department of Health and Human Services grants and one dedicated revenue account.

1. The federal Centers for Disease Control and Prevention, a three-year, $160,000/year grant (2020-2024) funds the following:
    - Fifty percent of the State Maine CDC Newborn Hearing Program Coordinator position, which also includes 50 percent of the rent, computer, and telephone services.
    - A contract with Nebulogic to support the maintenance and enhancement of the Maine CDC Newborn Hearing Program's updated data tracking and surveillance system.
    - Travel to attend the National Early Hearing Detection and Intervention Grantee annual meeting. This year the conference was held virtually due to coronavirus. Covered cost of registration.

2. The Maternal and Child Health Block Grant, through the Health Resources and Services Administration (HRSA), funds the following:
    - Fifty percent of the State Maine CDC Newborn Hearing Coordinator position, which also includes 50 percent of the rent, computer, and telephone services.

Goals and Activities

Nationally, there are seven goals to achieving a comprehensive, coordinated, community-based system of services:

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 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 that is babies born in 2020.

Hearing Screen Data

The primary goal of the Maine CDC Newborn Hearing Program is to ensure that every child born in Maine is screened for hearing loss and 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 97 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% 2020

In 2020, the Maine CDC Data, Research, and Vital Statistics reported a total of 11,300 births in Maine. The total number of infants screened was 10,939 (97%), 95% of infants received a screening within the first month of birth. The percentage of Maine newborns who "passed" a screening was 97 percent or 10,610 infants. A total of 329 infants (3%) did "not pass" the initial screen and any subsequent rescreening and were subsequently "referred."

Table 1: Number of Infants Not Screened in 2020

Total not screened	Infant died	Parents declined screening	Parents Contacted but Unresponsive	Transferred out-of-state	Went straight to Audiologist	Missed
361 (3%)	58	15	6	13	38	231

Data Source: CDC/NCBDDD/EHDI 2020

Further analysis of the 231 infants who "missed" the newborn hearing screen reveals 210 were home births.

Diagnostic Data

According to the National Center for Hearing Assessment and Management, 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: 55.6% in 2020

As reported above, the percentage of newborns who were "referred" after the initial screen and any subsequent rescreening was 3 percent or 329 infants. Eighty percent (261) of infants who were referred on their hearing screen received a diagnostic evaluation, and the program received a report. Seventy percent (183) of those children received a diagnostic evaluation no later than three months of age.

The Maine CDC identified the following as challenges to meeting the target goal of 72.6% receiving an audiological evaluation: COVID-19 has impacted the availability of pediatric audiologists to see patients, and some families were unresponsive or did not pursue evaluation services within the first 3 months.

Table 2: The percentage and number of infants who received an audiological (diagnostic) evaluation during 2020

Diagnostic Evaluation			
Total not pass "refer"	**Total infants with normal hearing**	**Total infants diagnosed with hearing loss**	**Total infants with no diagnosis**
329	232 (71%)	29 (9%)	68 (20%)

Data Source: CDC/NCBDDD/EHDI 2020

Further analysis of the 68 newborns with no diagnosis reveals the following:

- Nine children were non-residents
- Sixteen families declined follow-up
- Twenty-five families were unresponsive to multiple attempts at contact
- One child was rescreened and passed but data was not sent to the program
- Seventeen children's diagnostics were not completed for reasons unknown

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: 43.3% for 2020

There was a total of 29 infants diagnosed with hearing loss who did not pass their newborn hearing screen. All 29 (100%) were referred to Child Development Services (CDS), Part C Early Intervention (EI) Services. The Maine Newborn Hearing Program received confirmation that 20 children were receiving early intervention services from CDS. Of the nine children not in receipt of CDS services, six children were not enrolled because the family declined services, CDS was unable to make contact with two of the families and for one child not enrolled, the reason is unknown.

Maine has fallen short of the target goal of 55% of children with confirmed hearing loss enrolled. Contributing factors include: a number of infants were not diagnosed within the first six months and thus not included in this analysis, available services were impacted by COVID-19, while some families did not respond to outreach or otherwise were not able to be contacted.

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	20 (66.7%)	13 (65%)

Data Source: CDC/NCBDDD/EHDI 2020

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 (CDS) is responsible for the Part C services. For quality assurance and improvement, CDS provides aggregate data to the Department on the number referrals for early intervention services and the number determined eligible. Annually, the Department reviews the cooperative agreement with Maine’s Department of Education – Child Development Services.

Appendix A

2020 Early Hearing Detection and Intervention Data
January 1, 2020 – December 31, 2020

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	**11,300**	
Hospital births	10,995	97%
Non-hospital births	305	3%
SCREENING DATA		
Screened	**10,939**	**97%**
Hospital births screened	10,844	99%
Home birth screened	95	31%
Screen complete by 1 month	10,741	98%
Not screened	**361**	**3%**
Went straight to audiology diagnostic evaluation	38	
Infant died	58	
Parents declined services	15	
Non-resident	7	
Infant transferred out of state, no documentation of screen	6	
Unable to be screened due to medical reasons	0	
Missed screening	237	3%
Missed-home birth	210	
Missed-unresponsive	6	
Missed-screened but data not submitted to MNHP	4	
Missed- unknown	17	
Pass screening	**10,610**	**97%**
Did not pass screening	**329**	**3%**
DIAGNOSTIC DATA		
Did not pass screening-MNHP received audiological report w/diagnosis complete	**261**	**79%**
Diagnosis complete by 3 months	183	68%
Hearing normal	232	
Hearing loss	29	
Total-no diagnosis received	**68**	
Infant died	0	
Non-resident/Moved out of state	9	
Unable to test due to medical reasons	0	
Audiological Diagnosis in Process	0	
Family declined follow-up	16	
Completed but results not submitted to MNHP	1	

Lost to documentation/follow-up	**42**	
EARLY INTERVENTION DATA		
Refer NHS, Hearing Loss, referred to Part C provider-CDS	**29**	**100%**
Refer NHS, Hearing Loss-MNHP received confirmation of enrollment with Part C Provider-CDS	**20**	**69%**
Documentation of IFSP date received	20	100%
Enrolled in EI by 6 months	**13**	**45%**
Family contacted but unresponsive	0	
Family declined EI	6	
Ineligible for Part C Services	0	
Lost to documentation/follow-up	**4**	**14%**
Unable to contact	2	
Unknown	2	

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