

Maine's Newborn Hearing Screening Advisory Board Report

2024 Annual Report 1/1/2024 to 12/31/2024

Pursuant to: 22 MRS, §8823

Submitted by: Maine Department of Health and Human Services Maine Center for Disease Control and Prevention

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EXECUTIVE SUMMARY

Background

The Newborn Hearing Program within the Department of Health and Human Services – Maine Center for Disease Control and Prevention (Maine CDC) was established by the Legislature in 2000. 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." (22 M.R.S. §§ 8821-8825).

Maine's Newborn Hearing Screening Advisory Board was created to provide oversight to the Maine CDC Newborn Hearing Program and advise the commissioner on issues relating to the program. (5 M.R.S. §12004-G, sub§ 14-C). 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 for hearing loss to the Joint Committee on Health and Human Services.

Highlights

This annual 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). The data in this 2024 report reflects hearing screening and related services for babies born in 2022 and related program activities.

Screening (Total number of births 11,730)

- Ninety-six percent (11,226) of Maine newborns completed a newborn hearing screen.
- Four percent (504) of Maine newborns were not screened in 2022; the majority of these unscreened newborns, 55 percent (279) were home births, and 10 percent (52) went, without a reported screening, directly for a diagnostic evaluation.
- Ninety-seven percent (10,931) of those Maine newborns screened "passed" the screening.
- Three percent (295) received a "refer" result for further audiological evaluation.

Audiological Evaluation

- Eighty five percent (294) of 347 infants who received a "refer" result for further audiological evaluation or who, without a reported screening, received a diagnostic evaluation, were reported to have received a completed audiological evaluation.
 - Of these 294, 9 percent (26) were identified with a hearing loss and 91 percent (268) were found to have hearing within normal limits.

Early Intervention

- One hundred percent (26) 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 25 of those 26 infants were entered into early intervention services.
 - Of the 25 reported receiving early intervention services, 64 percent (16) of infants with a confirmed hearing loss were receiving early intervention services by six months of age.

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 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 Legislature in 2000 to provide oversight and advise the program and make recommendations to the commissioner for hearing screening, evaluation, intervention services. In 2007, the statute has been further amended and includes the coordination with Maine's Department of Education for Child Development Services System (CDS). Under the authority of 22 M.R.S. § 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 three years of age who are deaf or hard-of-hearing.

Maine CDC Newborn Hearing Advisory Board

The Board consists 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 M.R.S., 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 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.

Audiologist –	Physician –		
Nicole Duncan	Duska Thurston, MD		
Speech-Language Pathologist –	Nurse –		
Cathy Janelle	Erica Weightman		
Certified teacher of the deaf –	ECFS EI service provider –		
Donna Casavant, (Co-Chair)	Chelsea Alexander		
Culturally Deaf person –	Hard of hearing or deaf person –		
Catherine Lushman	Vacant		
Parent of a child who is Culturally Deaf –	Parent of a hard of hearing or deaf child –		
Jennifer Gaulin	Laura Sweet		
Parent of a hearing child –	Representative of hospitals –		
Vacant	Vacant		
Representative of health insurance carriers	Representative of CDS –		
Vacant	Ariana Whiting, LMSW-cc		
Representative of DHHS –	Other –		
Stephanie Lavigne	Susan Delaney, CPM, (Chair)		
Other –			

The Maine CDC Newborn Hearing Advisory Board Members, December 31, 2024

During calendar year 2024, the Board met three times. Two meetings were virtual and one meeting was hybrid. The board conducted business that included discussions on:

- Issues connected with vacancies on the Board
- Reconvened Board QI, Education and Membership Subcommittees
- Cytomegalovirus (CMV) Screening
- Ongoing work of the Program and challenges faced by the Program
- The submission of the US CDC EHDI data for Maine¹
- Reviewing and updating the Maine CDC Newborn Hearing Program publications and brochures
- Screening home birth babies
- COVID-19 impacts

Members of the public interested in attending board meetings should contact the Maine Newborn Hearing Program Coordinator.

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

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 three 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 three federal U.S. Department of Health and Human Services grants and one dedicated revenue account.

- 1. The federal Centers for Disease Control and Prevention, five-year, \$169,000/year grant (2020-2025) funds the following:
 - Fifty percent of the State Maine CDC Newborn Hearing Program Coordinator position, which also includes 50% 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 data tracking and surveillance system.
 - Travel to attend the National Early Hearing Detection and Intervention Grantee annual meeting. This year the conference was held in Denver, Colorado. The grant also covered the 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% of the rent, computer, and telephone services.
- 3. The Early Detection and Intervention State/Territory Program Grant, five-year, \$235,000/year grant (2024-2029) plus one year \$75,000 additional funds for optional EHDI Innovation Project Additional Activity (2024) through the Health Resources and Services Administration (HRSA), funds the following:
 - Travel to attend the 2025 National Early Hearing Detection and Intervention Conference. Also covers the cost of registration. This year the conference is in Pittsburgh, Pennsylvania.
 - A contract with Maine Educational Center for the Deaf and Hard of Hearing (MECDHH) to provide staff time for an audiology consultant and an early intervention specialist. Additionally, they are contracting with a quality improvement specialist and a parent consultant. The funds for the family-based organization, Maine Hands & Voices, Guide by Your Side, ASTra and D/HH Guides.
 - A contract with Nebulogic to develop a module for Maine CDC Newborn Hearing Program's data tracking and surveillance system to track language acquisition outcomes for Maine's deaf and hard of hearing children.

Goals and Activities

Nationally, there are seven goals to achieve 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 2022.

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.

From *Healthy People 2020²*:

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: 94% in 2022

The Maine CDC Data, Research, and Vital Statistics reported a total of 11,730 births in Maine in 2022. The total number of infants screened for hearing loss was 11,226 (96%), 94 percent of infants received a screening within the first month of birth. The percentage of Maine newborns who "passed" a screening was 97 percent or 10,931 infants. A total of 295 infants (3%) did "not pass" the initial screen and any rescreening and were subsequently "referred."

² <u>Healthy People - Healthy People 2020</u>

Reason for No Screening						
Missed	Infant fatality	Other*				Parents Contacted with no Response
298**	58	57	52	16	16	7

Data Source: CDC/NCBDDD/EHDI 2022

*Other – 57 infants were screened but data was not uploaded by the facility to the Maine CDC Newborn Hearing Program's data tracking and surveillance system

**Further analysis of the infants who "missed" the screening identified that 279 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.

From Healthy People 2020:

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: 85% in 2022

As reported above, the percentage of newborns who were "referred" after the initial screen and any subsequent rescreening was 3 percent or 295 infants and 12 percent or 52 infants did not have a newborn hearing screening and went straight to diagnostic evaluation, a total of 347 infants. Eighty five percent (294) of infants who were referred on their hearing screen and infants that went straight to diagnostic evaluation. Eighty-seven percent (256) 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 2022

Diagnostic Evaluation			
Total not pass "refer" and went directly to Diagnostic	Total infants with normal hearing	Total infants diagnosed with hearing loss	Total infants with no diagnosis
347	268 (77%)	26 (8%)	53 (15%)

Data Source: CDC/NCBDDD/EHDI 2022

Further analysis of the 53 newborns with no diagnosis reveals the following:

- One child died
- Four children were non-residents
- Ten families declined follow-up
- Seventeen families were unresponsive to multiple attempts at contact
- Two children were rescreened and passed but data was not sent to the program
- Fourteen children were marked as passed by Birth Facility RN in error or missed by Birth Facility.
- Three children went to audiologist, but we did not receive report from audiologist.
- One child 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.

From Healthy People 2020:

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: 61.5% for 2022

There was a total of 26 infants diagnosed with hearing loss who did not pass their newborn hearing screen or went straight to diagnostic evaluation. All 26 (100%) were referred to Child Development Services (CDS), Part C Early Intervention (EI) Services. The Maine Newborn Hearing Program received confirmation that 25 children were receiving early intervention services from CDS. One child was not enrolled and the reason is unknown.

Table 3: Percentage and number of children enrolled in Part C early intervention services following a diagnosis of hearing loss.

Total Children Enrolled in Part C			
	Total enrolledTotal enrolled before 6 months of age		
Children	25 (96.2%)	16 (64%)	

Data Source: CDC/NCBDDD/EHDI 2022

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

2022 Early Hearing Detection and Intervention Data January 1, 2022 – December 31, 2022

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	11,730	
Hospital births	11,335	97%
Non-hospital births	395	3%
SCREENING DATA		
Screened	11,226	96%
Hospital births screened	11,110	99%
Home birth screened	116	22%
Screen complete by 1 month	11,046	98%
• • •	50.4	40/
Not screened	504	4%
Went straight to audiology diagnostic evaluation	52	
Infant died	58	
Parents declined services	16	
Non-resident	0	
Infant transferred out of state, no documentation of	16	
screen		
Unable to be screened due to medical reasons	0	
Missed screening	362	3%
Missed-home birth	279	
Missed-unresponsive	7	
Missed-screened but data not submitted to MNHP	57	
Missed- unknown	19	
Pass screening	10,931	97%
Did not pass screening	295	3%
DIAGNOSTIC DATA		
Did not pass screening or went straight to diagnostics- MNHP received audiological report w/diagnosis complete	294	85%
Diagnosis complete by 3 months	256	87%
Hearing normal	268	0,770
Hearing loss	26	
Total-no diagnosis received	53	
Infant died	1	
Non-resident/Moved out of state	4	
Unable to test due to medical reasons	0	
Audiological Diagnosis in Process	0	
Family declined follow-up	10	
Completed but results not submitted to MNHP	3	
Lost to documentation/follow-up	35	

EARLY INTERVENTION DATA			
Hearing Loss, referred to Part C provider- CDS	26	100%	
Refer NHS, Hearing Loss-MNHP received confirmation of enrollment with Part C Provider-CDS	25	96%	
Documentation of IFSP date received	25	100%	
Enrolled in EI by 6 months	16	62%	
Family contacted but unresponsive	0		
Family declined EI	0		
Ineligible for Part C Services	0		
Lost to documentation/follow-up	1	4%	
Unable to contact	0		
Unknown	1		