

MAINE STATE LEGISLATURE

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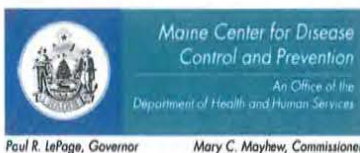
Maine CDC Newborn Hearing Advisory Board



*January 1, 2014 –
December 31, 2014*

Submitted to the Joint Standing Committee on Health and Human Services

2014 Annual Report





Paul R. LePage, Governor

Mary C. Mayhew, Commissioner

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January 30, 2015

Senator Eric L. Brakey, Chair
Representative Drew Gattine, Chair
Joint Standing Committee on Health and Human Services
#100 State House Station
Augusta, ME 04333-0100

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

Attached please find the 2014 Annual Report to the Legislature for the Maine CDC Newborn Hearing Program submitted by the Department of Health and Human Services. This report is required under Title 22 of the M.R.S.A., Chapter 1686. The report discusses the percentages of Maine infants screened, evaluated and being offered and receiving early intervention services and treatment.

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 Program.

Sincerely,

Mary C. Mayhew
Commissioner

MCM/klv

Attachment

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EXECUTIVE SUMMARY

January 2015

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 2012 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 2013 data will be available in February 2015.

Screening

- Ninety-eight percent (12,086) of Maine newborns completed a newborn hearing screen.
- Ninety-eight percent (11,901) of those Maine newborns screened by age one month or less “passed”.
- Of infants screened, two percent (208) received a “refer” result for further diagnostic evaluation.
- Two percent (260) of Maine newborns were not screened in 2012; the majority of these newborns 60% (157) were home births.

Audiological Evaluation

- Seventy-three percent (151) of those infants who did not pass (received a “refer” result) were referred and received a completed audiological evaluation in 2012;
 - Fourteen percent (23) were identified with a hearing loss and 84% (128) were evaluated and were found to have hearing within normal limits.

Early Intervention

- One hundred percent (23) of Maine children with a confirmed hearing loss were referred to the Department of Education's Child Development Services (Part-C).
 - The Maine Newborn Hearing Program received information that fifty-six percent (13) infants aged six months and under with a confirmed hearing loss were receiving early intervention services in 2012.

For more information on MNHP: Contact *Betsy Glencross, Newborn Hearing Coordinator*, betsy.glencross@maine.gov or 207-287-8427 www.mainepublichealth.gov/MNHP

Maine CDC Newborn Hearing Advisory Board

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 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.)

Funding Sources

The Maine CDC Newborn Hearing Program (MNHP) is entirely funded through two Federal U.S. Department of Health and Human Services Grants identified below:

- The Federal Centers for Disease Control and Prevention, a five-year \$150,000/year grant (2011-2016) that funds the following:
 - 50% of the State MNHP Coordinator position, which also includes 50% of the rent, computer and telephone services and parking.
 - 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 Annual meeting.

- The Maternal and Child Health Bureau/Division of Children with Special Health Needs three-year \$300,000/year grant (2014-2017) that funds the following:
 - 50% of the State MNHP Coordinator position, which also includes 50% of the rent, computer and telephone services and parking.
 - A contract with the Maine Center for the Education of the Deaf and Hard of Hearing for the provision of a:
 - Full time follow-up coordinator,
 - Half time parent consultant,
 - Part time pediatric audiologist, and
 - Support for Guide By Your Side—a parent-to-parent program that provides support to families of a newly-diagnosed child who is deaf or hard of hearing by linking with other families and providing resources.
 - 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."

- Two portable hearing screeners to screen babies who are born at home.
- The purchase of pamphlets, brochures and informational packets to support education to various groups including families.

National Goals

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.

State Advisory Board

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.

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, a person who provides early intervention services 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 hearing child and a representative of each of the following: hospitals, health carriers, early childhood special education program under Title 20-A, Chapter 303, and 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 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, 2014**

Audiologist – Eileen Peterson, M.S., FAAA	Physician – Christopher Pezzullo, D.O.
Speech-Language Pathologist – Louise Packness, CCC-SLP	Nurse – Nola Metcalf, RN-C
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 – Romy Spitz, Ph.D.
Parent of a child who is Culturally Deaf – Vacant	Parent of a hard of hearing or deaf child – April Morin
Parent of a hearing child – Sarah Pierce Bureau	Representative of hospitals – Annette Bowman, RN
Representative of health insurance carriers – Karen Harrison (Co-Chair)	Representative of CDS – Kim Appleby
Representative of DHHS – Vacant	Other – Bethany Picker, MD
Other – Harriet Gray, Ph.D. (Co-Chair)	

The Board is aggressively seeking prospective members to fill the two current vacancies.

During 2014, MNHP Advisory Board met three times and reported the following achievements:

- With a continued focus on quality improvement, identified the parameters for Maine CDC Newborn Hearing Program dashboard that will present timely, actionable data for Board members. The dashboard is currently in development and will be available after spring 2015.
- Updated Board guidelines and committee assignments and scope.
- Addressed changes in Board membership by engaging in discussions of how to identify key expertise to fill open seats.
- Received training on current topics that impact the Program, including assessment techniques, early intervention and family-centered follow-up.

**Maine CDC Newborn Hearing Program
Summary of the 2012 Data**

This report uses 2012 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 to describe screening, evaluation, early intervention services and the demographic characteristics of the population. The 2013 screening data will be available in February 2015.

The U.S. Department of Health and Human Services has established national health objectives to be achieved by the end of 2020. These objectives known as *Healthy People 2020*, includes the following goal related to Newborn Hearing Screening:

- Increase the proportion of newborns screened for hearing loss by no later than age one month,
- Increase the number of newborns with complete audiological evaluation by age three months, and
- Increase the number of newborns who are enrolled in appropriate intervention services no later than age six months.

The Joint Committee on Infant Hearing recommends the routine monitoring of established benchmarks for the purpose of 1) setting organizational goals; 2) identifying indicators to measure progress toward achieving those objectives; and 3) identifying areas that require a focused quality improvement process.

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 the Department of Education, Child Development Services for early intervention services. *Healthy People 2020* set the benchmark for screening no later than age one month at 90.2%. Maine continues to exceed the goal with a screening rate of 98%.

Objective: Increase the proportion of newborns who are screened for hearing loss no later than age 1 month

Baseline: 82.0 percent of newborn aged one month or less had screening for hearing loss in 2007.

Target: 90.2 percent

Achieved: 98.0% 2012

In 2012, the Maine CDC Data, Research and Vital Statistics reported that there were a total of 12,590 births in Maine. The total number of infants screened was 12,330 (98%). The percentage of Maine newborns that “passed” a screening by one month of age was 98% or 11,901 infants. A total of 208 infants (1.6%) did not “pass” the initial screen and any subsequent rescreening and were subsequently “referred”.

Table 1: Percent and number of infants screened during 2012

Screening						
Total Occurrent Births	Total Screened	Total Pass	Total Pass before 1-month of age	Total pass after 1-month but before 3-months of age	Total pass after 3-months of age	Total did not pass “refer”
12,590	12,330 (98%)	12,122 (98%)	11,901 (98%)	179(1.4%)	42 (0.3%)	208 (1.6%)
Data Source: CDC/NCBDDD/EHDI 2012						

Table 2: Number of infants not screened in 2012

Infants not Screened				
	Total not screened	Infants died	Parents declined screening	Missed
	260 (2.0%)	67	20	173
Data Source: CDC/NCBDDD/EHDI 2012				

Further analysis of the 173 infants who “missed” the newborn hearing screen reveals the following: 157 were home births; eight families were unresponsive to any contact made by the Maine CDC Newborn Hearing Program; and eight moved or were transferred out of state.

Advisory Board Recommendations

- Continue to educate hospital administrators, nurse managers and other stakeholders to maintain the current screening rate of 98%
- Partner with the Maine Association of Certified Professional Midwives (MACPM) to improve the system for screening infants when they are born outside of the hospital system.
- Purchase several portable screeners for MACPM personnel to expand access to screening for families who choose to deliver at home.
- Work with Birth Wise Midwifery School to present information to students on the importance of newborn hearing screening.

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 percent of infants aged three months and under who did not pass the hearing screening received audiological evaluation in 2007.

Target: 72.6 percent

Achieved: 72% in 2012

As reported above the percentage of newborns who failed “referred” the initial screen and any subsequent rescreening was 2% or 208 infants. During 2012, a total of 73% (151) infants did receive a diagnostic evaluation. However, only 108 infants (72%) received a diagnostic evaluation no later than three months of age.

Table 3: The percent and number of infants who received an audiological (diagnostic) evaluation during 2012.

Diagnostic Evaluation					
	Total not pass “refer”	Total receiving diagnostic evaluation before 3-months of age	Total receiving diagnostic evaluation after 3-months of age but before 6-months of age	Total receiving diagnostic evaluation after 6-months of age	Total with no diagnostic evaluation
	208	108 (72%)	16 (8%)	27 (13%)	57 (27.4%)
Data Source: CDC/NCBDDD/EHDI 2012					

Further analysis of the 57 newborns with no diagnosis reveals the following: nine families moved out of state; ten families declined any further services; 19 families were unresponsive to multiple attempts at contact; MNHP was unable to contact six families because of missing or incorrect contact information and the PCP was unknown; seven children were seen by an audiologist but the testing was incomplete; and, six children defined as “Other” which includes but is not limited to the following reasons: out of state results were not obtainable; audiologic evaluation was not completed; medical reasons prevented testing and PCP did not refer for diagnostic follow-up

Table 4: Percent and number of infants identified with hearing loss and referred on newborn hearing screen and confirmed with a hearing loss during 2012

Total identified with hearing loss and referred on newborn hearing screen				
	Total with confirmed hearing loss	Total hearing loss identified before 3-months of age	Total hearing loss identified after 3-months of age but before 6-months of age	Total hearing loss identified after 6-months of age
	23	13(57%)	3 (13.0%)	7(30.4%)
Data Source: CDC/NCBDDD/EHDI 2012				

Table 5: Total number of children with hearing loss and who passed/missed newborn hearing screen 2012

Total identified with hearing loss and who passed/missed newborn hearing screen				
	Total with confirmed hearing loss	Total hearing loss identified before 3-months of age	Total hearing loss identified after 3-months of age but before 6-months of age	Total hearing loss identified after 6-months of age
	24	1 (4.1%)	0	23 (95.8%)
Data Source: CDC/NCBDDD/EHDI 2012				

A total of 47 children were identified with a confirmed hearing loss. Twenty-three of these children referred on their newborn hearing screen. Twenty-four 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).

Advisory Board Recommendations

- Work with audiologists to encourage the use of the on-line reporting form.
- Monitor audiological referrals/FAXs from birthing facilities via ChildLINK
- Educate and encourage all birthing centers to make audiological referrals for infants who do not pass their newborn hearing screen.
- Request newborn screening policies from hospitals to ensure that the policy includes making referrals to audiologists prior to discharge for infants who do not pass their newborn hearing screen.
- Work with hospitals and ChildLINK to improve timeliness of reported equipment failures and data errors.
- Survey hospitals to determine if barriers exist that prohibit them from scheduling audiological appointments and notifying MNHP and the child's PCP.
- ChildLINK should automatically notifies EHDI Coordinator when audiology report is received
- Review "at risk" children and recommend follow-up diagnostic evaluations.
- Collaborate with the other New England states to develop a quality improvement project that improves early access to border babies thereby decreasing Lost to Follow-up/Diagnosis (LFU/D).
- Encourage audiologists to register with the EHDI-PALS (Pediatric Audiology Links to Services) website.

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 percent of infants aged six months and under with confirmed hearing loss were enrolled for intervention service in 2007.

Target: 55.0 percent

Achieved: 77.0% for 2012

During 2012, there were a total of 23 infants diagnosed with hearing loss. All 23 (100%) were referred to Department of Education, Child Development Services, Part C Early Intervention Services. The Maine Newborn Hearing Screening received confirmation that 13 children were receiving early intervention services from either the Department of Education's Child Development Services or from the Maine Education Center for the Deaf and Hard of Hearing's

Early Child and Family Services Program. The Program was unable to confirm that the remaining 10 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. The Maine CDC Newborn Hearing Program can confirm that two families refused any further services, leaving a total of eight children (34.7%) who would be considered lost to follow-up.

Table 6: Percent and number of children enrolled in Part C and Non-Part C early intervention services.

Total children enrolled in Part C and Non-Part C					
	Total Enrolled	Total enrolled before 6 months of age	Total after 6 months of age but before 12 months of age	Total enrolled after 12 months of age	Enrolled but age is unknown
Part-C and Non-Part C	13	10 (77%)	2 (15.3%)	1 (7.6%)	0
Data Source: CDC/NCBDDD/EHDI 2012					

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

Non-Part C service provider is defined as anyone who is not affiliated with or receives any funds from the Department of Education, IDEA Part C Program. This includes, among others, a privately-owned early childhood center that offers therapy for disabled children, a not-for profit privately-owned speech and hearing clinic that offers therapy for children with hearing loss, a university-based early childhood center that offers therapy. In other words, any therapy a child is enrolled in that is not managed by Part C can be considered “non-part C.”

Advisory Board Recommendations

- Provide outreach and education to all CDS site Directors to increase knowledge and awareness of MNHP.
- Establish regular meetings with Maine Education Center for the Deaf and Hard of Hearing staff to improve outcomes for children.
- Work with Department of Education/Child Development Services and Maine Education Center for the Deaf and Hard of Hearing/Early Child and Family Services to ensure that MNHP is included on the release of information.

**Appendix A – 2012 DEMOGRAPHIC DATA – Screening
January 1, 2012 – December 31, 2012**

	Screening				
	Total Occurrent Births	Total Pass	Total Pass Before 1 Month	Total Not Pass	Total Not Pass Before 1 Month
Totals	12590	12122	11901	208	185
Sex					
Male	6490	6235	6116	114	101
Female	6100	5887	5758	94	84
Unknown	0	0	0	0	0
Maternal Age					
<15 years	4	4	4	0	0
15 – 19 years	585	574	559	8	8
20 – 24 years	2830	2750	2695	46	42
25 – 30 years	7276	6987	6868	124	109
35 – 50 years	1891	1804	1772	30	26
> 50 years	4	3	3	0	0
Maternal Age Unknown	0	0	0	0	0
Maternal Education					
< High School	1233	1171	1143	34	31
High School Graduate or GED	4005	3875	3804	66	60
Some College or AA/AS Degree	3115	2014	2954	43	39
College Graduate or above	4186	4023	3967	63	53
Unknown	51	39	36	2	2
Maternal Ethnicity					
Hispanic or Latino	201	196	186	3	3
Not Hispanic or Latino	12377	11918	11709	205	182
Unknown	12	8	6	0	0
Maternal Race					
White (Not Hispanic)	11592	11163	10967	192	170
White (Hispanic)	173	170	160	1	1
White (Ethnicity Unknown)	5	2	2	0	0
Black or African American (Not Hispanic)	396	379	370	12	11
Black or African American (Hispanic)	19	19	19	0	0
Black or African American (Ethnicity Unknown)	0	0	0	0	0
Asian	231	227	223	2	2
Native Hawaiians & Other Pacific Islanders	1	1	1	0	0
American Indian & Alaska Natives	128	127	125	1	1
Unknown	14	7	7	0	0
Other	31	27	27	0	0

Data Source: CDC/NCBDDD/EHDI 2012

Appendix B – 2012 DEMOGRAPHIC DATA – Diagnostics
January 1, 2012 – December 31, 2012

Diagnosis				
	Normal Hearing	Normal Hearing Before 3 Months	Hearing Loss	Hearing Loss Before 3 Months
Totals	128	95	23	13
Sex				
Male	70	52	11	6
Female	58	43	12	7
Unknown	0	0	0	0
Maternal Age				
<15 years	0	0	0	0
15 – 19 years	7	4	0	0
20 – 24 years	29	20	4	2
25 – 30 years	74	57	17	10
35 – 50 years	18	14	2	1
> 50 years	0	0	0	0
Maternal Education				
< High School	21	15	4	1
High School Graduate or GED	43	25	7	5
Some College or AA/AS Degree	26	23	7	5
College Graduate or above	36	30	8	5
Unknown	2	2	0	0
Maternal Ethnicity				
Hispanic or Latino	3	3	0	0
Not Hispanic or Latino	176	138	22	11
Unknown	0	0	0	0
Maternal Race				
White (Not Hispanic)	117	87	21	13
White (Hispanic)	1	1	0	0
White (Ethnicity Unknown)	0	0	0	0
Black or African American (Not Hispanic)	9	6	1	0
Black or African American (Hispanic)	0	0	0	0
Black or African American (Ethnicity Unknown)	0	0	0	0
Asian	1	1	0	0
Native Hawaiians & Other Pacific Islanders	0	0	0	0
American Indian & Alaska Natives	0	0	1	0
Unknown	0	0	0	0
Other	0	0	0	0
Data Source: CDC/NCBDDD/EHDI 2012				

Appendix C – 2012 DEMOGRAPHIC DATA – Early Intervention
January 1, 2012 – December 31, 2012

Early Intervention				
	Total Enrolled in Part C EI	Total Enrolled in Part C EI Before 6 Months	Total Services Non-Part C EI	Total Services Non-Part C EI Before 6 Months
Totals	11	9	2	1
Sex				
Male	6	5	1	1
Female	5	4	1	0
Unknown	0	0	0	0
Maternal Age				
<15 years	0	0	0	0
15 – 19 years	0	0	0	0
20 – 24 years	2	2	0	0
25 – 30 years	8	6	2	1
35 – 50 years	1	1	0	0
> 50 years	0	0	0	0
Maternal Education				
< High School	0	0	1	0
High School Graduate or GED	5	4	0	0
Some College or AA/AS Degree	1	1	1	1
College Graduate or above	5	4	0	0
Unknown	0	0	0	0
Maternal Ethnicity				
Hispanic or Latino	0	0	0	0
Not Hispanic or Latino	11	9	2	1
Unknown	0	0	0	0
Maternal Race				
White (Not Hispanic)	11	9	2	1
White (Hispanic)	0	0	0	0
White (Ethnicity Unknown)	0	0	0	0
Black or African American (Not Hispanic)	0	0	0	0
Black or African American (Hispanic)	0	0	0	0
Black or African American (Ethnicity Unknown)	0	0	0	0
Asian	0	0	0	0
Native Hawaiians & Other Pacific Islanders	0	0	0	0
American Indian & Alaska Natives	0	0	0	0
Unknown	0	0	0	0
Other	0	0	0	0

Data Source: CDC/NCBDDD/EHDI 2012