

**Maine Department of Human Services
Bureau of Health – Division of Family Health
Maine Newborn Hearing Program
Chapter 279**

RULES RELATING TO THE MAINE NEWBORN HEARING PROGRAM

SUMMARY:

These rules define 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. These rules address the documentation of information provided to parents; designation of a contact person in each hospital; timing of hearing screening; parental refusal of hearing screening; types of records to be maintained; data to be reported; responsibilities for follow-up tests when necessary; documentation of results and contact with families.

1.0 PURPOSE

1.1 These rules implement the Maine Newborn Hearing Program as established pursuant to Public Law 647, 22 MRSA c. 1686. The rules are adopted under the authority of 22 MRSA § 8825 of the Maine Revised Statutes.

2.0 DEFINITIONS

2.1 “Audiologist” means an individual who practices audiology and who by virtue of academic and practical training presents himself to the public by any title or description of services incorporating the words, Audiologist, Hearing Clinician, Hearing Therapist or any similar title or description of services. Maine law requires an audiologist to hold a license to practice in accordance with standards set forth by the Maine Department of Professional and Financial Regulations.

2.2 “Birth Admission” means the time after birth that the newborn remains in the hospital nursery prior to discharge.

2.3 “Birthing Center” means any non-hospital health facility, institution, or place designed to accommodate mothers giving birth away from home at the culmination of normal, uncomplicated deliveries.

2.4 “Birthing Hospital” shall mean, for purposes of rules regarding newborn hearing screening, a hospital with a maternal and newborn service.

2.5 “Board” means the Maine Newborn Hearing Program Advisory Board.

2.6 “Department” means program leadership, management or staff from the Department of Human Services, Bureau of Health, Maine Newborn Hearing Program.

2.7 “Hearing Loss” means a hearing loss of 16 decibels or more in the frequency region important for speech recognition and comprehension in one or both ears.

2.8 “Hearing Screening” means a physiologic measure of a newborn’s hearing designed to detect if a newborn is at a high risk of having hearing loss.

2.9 “High Risk Indicator” means a diagnostic finding which causes an individual to be susceptible to hearing loss because of biological or environmental factors.

2.10 “Intervention” or “treatment” means the early intervention services described in the federal Individuals with Disabilities Education Act, 20 United States Code, Chapter 33, Subchapter III, Sections 1431 to 1445, as amended. “Intervention” or “treatment” includes, but is not limited to, audiological, medical, or early educational services that provide a choice of methods of communications in a variety of sensory modalities.

2.11 “Parent” means a natural parent, stepparent, adoptive parent, legal guardian or other legal custodian of a child.

2.12 “Pass Result” means a result from the newborn hearing screening which indicates that, as of the time of the screening, the newborn is likely to demonstrate normal hearing sensitivity in the test ear.

2.13 “Person who is culturally Deaf” means a person with permanent hearing loss who identifies as a member of the Deaf community and who utilizes American Sign Language as the primary mode of communication.

2.14 “Person who is hard-of-hearing” or “person who is deaf” means a person with permanent hearing loss who communicates using aural or oral skills for accessing spoken language.

2.15 “Program” means the Maine Newborn Hearing Program.

2.16 “Refer Pattern” means a result from a newborn hearing screening which indicates that the newborn may not demonstrate normal hearing in the test ear at the time of screening, and requires further screening or diagnostic assessment.

3.0 RESPONSIBILITY FOR HEARING SCREENING OF INFANTS BORN IN HOSPITALS IN MAINE

3.1 The administrator of the birthing hospital shall be responsible for providing information about the importance of newborn hearing screening and of receiving follow-up care. The information must explain the process of a newborn hearing screening, the likelihood of a child having a hearing loss, follow-up procedures and community resources and must include a description of the normal auditory, speech and language development process in children. This information must be provided to the parents of the newborn prior to discharge or by one month of age, whichever comes first, and must include information regarding the location of hearing facilities available to the newborn. The administrator of the birthing hospital may elect to provide newborn hearing screening at his/her facility or may coordinate, schedule or arrange for newborn hearing screening at another facility.

3.2 Each administrator of a birthing hospital or birthing center should appoint and provide to the Maine Newborn Hearing Program, the name of a contact person at the facility, who shall be responsible for coordinating the facility's hearing screening program or reporting record.

3.3 The person who actually performs the hearing screening shall be responsible for documenting the hearing screening results in the infant's chart and in the facility's designated reporting record. The documentation shall include the hearing screening method used, person performing the hearing screening, any high risk indicators observed and the results of the hearing screening.

3.4 No infant shall be discharged from a birthing hospital or birthing center until his/her medical record is checked to assure that it includes documentation of a hearing screening has been performed, scheduled or declined by the parents. In the event an infant is identified as having been discharged without appropriate documentation of hearing screening, the scheduling of a hearing screening appointment, or parental refusal of hearing screening, follow-up is required. Follow-up must occur within two business days of such identification. The contact person shall notify the Maine Newborn Hearing Program that the infant has been discharged without appropriate documentation of hearing screening, the scheduling of a hearing screening appointment or parental refusal of hearing screening.

3.5 In the event that an infant is transferred to another birthing hospital before the hearing screening has been completed, it is the responsibility of the second facility to assure that information regarding the importance of newborn hearing screening and follow-up care has been provided to the parents of the newborn. Such information shall be provided to the parents of the newborn prior to discharge, or within one month of age, whichever occurs first, and shall include the location of a facility wherein newborn hearing screening is available. The administrator of the birthing hospital may either offer to provide the newborn hearing screening at his/her facility, or to coordinate, schedule, or arrange for the newborn hearing screening to be provided at another facility.

3.6 In the event newborn infants are preterm, ill, in intensive care, or otherwise medically unstable, the administrator of the birthing hospital shall provide information regarding newborn hearing screening, as soon as practical and reasonable, after the newborn becomes medically stable.

3.7 Hospitals providing newborn hearing screening shall establish standards for appropriate documentation, data management and transmission of data for the Maine Newborn Hearing Program.

4.0 DATA ELEMENTS

4.1 Hospitals, birthing facilities and other providers of infant hearing screening shall provide the following information to the Maine Newborn Hearing Program on a weekly to bi-monthly basis:

- A. The number of infants born in that hospital or location and the number of infants who participated in hearing screenings during the birth admission.
- B. The number of infants who participated in hearing screening at that hospital or location who received a "pass result" from the screening.
- C. The number of infants who participated in hearing screening at that hospital or location who received a "refer pattern" from the screening.
- D. The number of infants recommended for follow-up rescreening at that hospital or location.
- E. The number of infants recommended for follow-up rescreening at another location.
- F. The number of infants recommended for monitoring related to high-risk indicators.
- G. The number of infants recommended for diagnostic audiologic evaluation.
- H. The number of infants whose parents declined the newborn hearing screening.

4.2 The birthing hospital, birthing center or other provider of infant hearing screening shall include the information necessary to allow identification of the infant for appropriate tracking and follow-up when reporting to the Program.

5.0 RESPONSIBILITY FOR HEARING SCREENING OF INFANTS BORN IN MAINE BUT NOT IN A HOSPITAL

5.1 In the event an infant is born outside a birthing hospital and the Department has received confirmation of the birth, the Department shall be responsible to provide information to the parents regarding the importance of screening the hearing of newborns and of receiving follow-up care. The information provided must explain the process of hearing screening, the likelihood of a child having a hearing loss, the potential for later onset of hearing loss related to high risk indicators, follow-up procedures and community resources. The Department shall be responsible to provide information, which includes a description of the normal auditory, speech and language development process in children. Within three months of birth, the Department shall provide information to the parents of the newborn regarding the availability of hearing screening.

6.0 PARENTAL REFUSAL OF NEWBORN HEARING SCREENING

6.1 In the event of a parental refusal for newborn hearing screening, the birthing hospital or birthing center shall be responsible to document such refusal, and such documentation shall be made part of the newborn's medical record. The birthing hospital, whenever practical and reasonable, shall obtain the parents' written refusal of hearing screening and provide a copy to the Maine Newborn Hearing Program.

7.0 PROGRAM'S RESPONSIBILITY TO MAINTAIN CONFIDENTIALITY OF ALL DATA

7.1 All data reported to the Program, which contains either direct or indirectly individually identifiable information shall be confidential and is not considered a public record.

7.2 Any report produced from data collection will be in a form that does not allow direct or indirect identification of individuals.

7.3 Information submitted to the Maine Newborn Hearing Program shall only be available to qualified organizations or individuals with a documented history of scientific research, or other researchers determined to be appropriate by the Program. All information shall be subject to confidentiality agreements as deemed appropriate by the Program.

7.4 A standard Institutional Review Board process conforming to all applicable state and federal laws is required for any proposed research plan that involves the use of any Maine Newborn Hearing Program data. Approval by the Maine Bureau of Health Institutional Review Board must be documented prior to the release of any data.

8.0 CONTACT WITH FAMILIES

8.1 The program may contact families to provide information about available services.

8.2 The family is not required to accept any referral or service.

8.3 Referral to outside agencies will be made only upon consent or request of parent.

9.0 ADVISORY BOARD

9.1 The Advisory Board shall oversee the administration of the Program, advise the Commissioner of the Department of Human Services on issues relating to the Program, and recommend procedures for hearing screening, evaluation, treatment and services. The Board will report each year to the joint standing committees of the Legislature having jurisdiction over health and human services matters and education matters on the program, the percentages of children being screened and evaluated and those children being offered and receiving intervention and treatment services. The report shall be made available to the public.

9.2 The Advisory Board shall consist of an odd number of members, numbering at least 15, appointed by the Governor, including but not limited to the following: an audiologist, a physician, a speech-language pathologist, a nurse, a certified teacher of the deaf and a person who provides early intervention services to children who are deaf or hard-of-hearing through the Governor Baxter School for the Deaf, a person who is culturally Deaf, a person who is hard-of-hearing or deaf and a parent of a hearing impaired child, a representative of the hospitals, a representative of health carriers, a representative of the Child Development Services System established in Title 20-A, section 7724 and a representative of the Department.

9.3 Advisory Board members may be reimbursed for reasonable and necessary expenses incurred to attend board meetings but are not entitled to per diem payments. The Department of Human Services shall provide financial and staff support for the Board.

BASIS STATEMENT:

These rules are adopted to define responsibilities related to screening of newborn infants for hearing loss and the tracking and follow-up of identified infants. With detection of infants who are deaf or hard-of-hearing at the earliest opportunity, services can be provided that promote the acquisition of language at a critical age and prevent developmental delays associated with the late attainment of fluent language and communication skills.

Effective Date: January 1, 2004