

MAINE STATE LEGISLATURE

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Forward

In 1999, the 119th Maine State Legislature enacted Public Law 1999, Chapter 647, establishing the Maine Newborn Hearing Program within the Department of Health and Human Services, Maine Center for Disease Control, Division of Family Health. 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.”

As of November 2000 all hospitals are required to provide information to the parents of newborns regarding the importance of a hearing screening. Hospitals are required to provide information about hearing screening that is either provided at the facility or “coordinated, scheduled, or arranged for by the hospital.” The same requirement was extended to all birthing facilities as of November 2002.

As of January 2003, every hospital and other birthing facilities are required to report the number of newborns born in the facility, the number of newborns screened prior to discharge, the number of newborns who passed the hearing screen, the number of newborns who were referred for further diagnostic evaluation, and the number of newborns whose parents declined screening.

The law further authorized the Department of Health and Human Services to establish a tracking system that effectively plans and establishes a comprehensive system of developmentally appropriate services for infants and children with hearing loss and their families.

Background

Hearing loss is one of the most common birth defects. Hearing loss often has no visual indicators and according to the Joint Committee on Infant Hearing, “hearing loss in newborns is not readily detectable by routine clinical procedures.” Historically, hearing loss often went undetected until a child began to experience delays in language development. At that point, parents and professionals began to seek answers and found that most often, the language delay was related to a hearing loss. Early identification of a

hearing loss provides the child and family an opportunity to introduce early interventions that enable a child with a hearing loss to progress at a rate similar to their hearing peers.

Research has shown that the most critical period for speech and language development is from birth to age three. Without newborn hearing screening, the average age of identification of congenital hearing loss is 2 ½ to 3 years of age, well beyond the most critical period for language development. The resulting delays in fluent language and communication capabilities can have a lifelong impact on the individual and can result in significant and irreversible cognitive and social delays.

Therefore, the Maine Newborn Hearing Program is comprised of the following three components to ensure that all children possess the necessary skills to develop language during this critical period.

- All Maine newborns will be screened for hearing loss by one-month of age, preferably before hospital discharge;
- All Maine infants who screen positive will have a diagnostic audiological evaluation before 3 months of age; and,
- All Maine infants identified with hearing loss will receive appropriate early intervention services before six months of age.

The Maine Newborn Hearing Program (MNHP)

This report provides an overview of the Maine Newborn Hearing Program, results from CY2007, Program activities for 2008 and planned activities for 2009. For more information on the Maine Newborn Hearing Program, visit the Program's website at http://www.maine.gov/dhhs/boh/cshn/hearing_screening/index.html

Overview of Program

Administration of the MNHP

The MNHP is housed with the Maine Department of Health and Human Services, Maine Center for Disease Control and Prevention, Division of Family Health, Children with Special Health Needs/Genetics Program.

Staffing and Funding

The MNHP staff consists of one full-time Newborn Hearing Coordinator. Program staff, maintenance of the tracking database called ChildLINK and other activities are

currently funded entirely through Federal grants from the Federal Center for Disease Control & Prevention and the Maternal and Child Health Bureau. The 3-year grants for both funding sources ended in 2008 and the Maine Newborn Hearing Program re-applied for and were awarded grants which should provide funding for the Program through 2011.

Maine Newborn Hearing Program Advisory Board

The Maine Newborn Hearing Advisory Board (MNHP) was established to oversee the program and to advise the MeCDC Director, Dr. Dora Anne Mills, MPH, on issues relating to the program and to make recommendations regarding procedures for hearing screening, evaluation, treatment, and intervention services. The MNHP Advisory Board is comprised of individuals appointed by the Governor. As of December 2008, the MNHP Advisory Board is pleased to report that fifteen seats on the Board are filled. The MNHP Advisory Board is currently working to secure a parent of a child who is deaf or hard of hearing and a person who is culturally deaf to fill the two vacant seats.

Reporting and Tracking System

The Maine Newborn Hearing Program was authorized by the legislature to implement a tracking system that provides the program with the necessary information to effectively plan, establish and evaluate a comprehensive statewide program that meets or exceeds the Federal CDC's Early Hearing Detection and Intervention (EHDI) guidelines. These guidelines were established to ensure that all infants are screened prior to one month of age; have a diagnostic audiological evaluation before three months of age if they screen positive; and, receive appropriate early intervention services before six months of age. In response, the MNHP established a cooperative agreement with the University of Maine – University Center of Excellence in Developmental Disabilities in Orono to develop an electronic tracking and follow up system. The ChildLINK data system was established and designed to meet the Maine Newborn Hearing Programs needs. ChildLINK is a data tracking system that links newborn hearing screening data with the electronic birth certificate, enabling the MNHP to verify that every baby born in Maine has a newborn hearing screen and to

track follow up services with regards to audiological evaluations and referrals to early intervention services.

Hospital Reporting

In 1999, nine Maine hospitals had established newborn hearing screening programs. At that time only 39% of all Maine infants had access to a newborn hearing screen. By 2002, thirty hospitals had established newborn hearing screening programs with 97% of infants having access to a newborn hearing screen. By 2003, all Maine birthing facilities had established newborn hearing screening programs. Each of these facilities can upload information electronically to ChildLINK or submit data to the MNHP for transfer to the database. There are currently 31 birthing facilities in Maine and all of them receive site visits, regular communication with the Program and technical assistance as appropriate. During 2008, one hospital and one free-standing birthing facility ceased offering maternity services due to financial reasons.

Audiology Reporting

Maine audiologists play an important role in providing diagnostic evaluations to infants who screen positive for hearing loss. The challenge to the MNHP was the lack of results being reported back to the Program. Therefore, working with the Maine Academy of Audiologists and the MNHP Advisory Board, the DHHS submitted legislation that required “all hospitals licensed in the State and other providers of services that have established hearing screening or diagnostic procedures for newborns, infants, and children up to 3 years of age shall report to the Department all data on hearing screening, evaluation, and diagnosis of newborns, infants and children up to age 3 years of age.” This resulted in the 123rd Maine State Legislature passing **P.L. 2007, Chapter 236 – An Act to Enhance the Newborn Screening Program** which became law in September 2007. This bill mandates that all providers of hearing diagnostic procedures report the results of their evaluation and diagnosis to the MNHP.

Program Evaluation

As part of our grant requirements for the Maternal and Child Health Bureau, the MNHP conducted a Parent Feedback Survey in May 2008 to help evaluate the Maine Newborn Hearing Program. The survey was sent to the 6750 families of children born

during the last six months of 2007. We had a response rate of 21%. The survey was designed to measure feedback from all parents, regardless of hearing screening results. Survey items included a demographic questionnaire, items regarding parents' knowledge of newborn hearing screening and their baby's results, and their level of satisfaction with the screening process, and if appropriate, their satisfaction with the referral and early intervention processes as well. The primary conclusions and recommendations based on the survey results are as follows:

- Increased education. The survey results clearly identified a need to increase education and involvement of parents in the newborn hearing screening process. Parents who had a homebirth noted a need for education directed at midwives and homebirth attendants. This education may help increase the likelihood that babies born at home will have their hearing tested, if not at the time of birth, at a separate appointment with their health provider.
- Continue quality improvement with hospitals. Based on feedback from parents, the MNHP will continue to work with hospitals on improving the quality of services including facilities and equipment used for newborn hearing screening.
- Improve survey. In an effort to improve and revise survey questions, future iterations of this survey will be pilot-tested with parents. Specifically, parents will be given more opportunity to provide comments related to experiences with and attitudes about newborn hearing screening. Additionally, a separate survey for each grouping of test results (i.e. passed, referred, hearing loss) will be developed.

Newborn Hearing Screening Reportable Data CY2007

Data submitted during CY2007, to ChildLINK revealed that 13,975 births occurred in Maine. Of these, 13,601(97.3%) were screened for hearing loss, with 13,328 of those babies screened by one month of age. Of the 13,601 screened, 312 (2.3%) were referred for audiological evaluations. To date, we have received 134 (44%) reports on those babies who were referred. Of the 134 reports we have received, 18 babies were identified with hearing loss. We have received no Individual Family Service Plan (IFSP) information from Child Development Services (CDS) in 2007. CDS is only required to send aggregated data on the number of children served with a hearing loss not

individualized information. We have proposed that CDS add MNHP to their release of information form, thus allowing CDS to MNHP individualized information on early intervention services.

As mentioned earlier, 100% of the birthing facilities are offering newborn hearing screening, as a standard of care. During CY2007 24 birthing facilities had a greater than 98% screening rate with three of these facilities obtaining a 100% rate. Four facilities had less than a 95% screening rate. The remaining 4 facilities had screening rates between 95% and 98%. It is unlikely that all 31 birthing facilities will reach 100% as the rate is based on the number of live births at each facility and does not take into account parent refusal or other instances where a baby dies shortly after birth.

Activities for 2008

- Conducted site visits as needed and provided technical assistance to all 31 birthing facilities.
- LD 1239 “Resolve, To Establish a Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine” was introduced and signed into law by Governor Baldacci and became effective in June 2007. In 2008, this task force met to examine issues of access to timely and accurate diagnosis of hearing loss by 3 months of age, and review the process by which families are informed of their options for communication and finding providers in the State. The MNHP was asked to provide data, information, and support for this task force. As a result of this work group, LD 2295, “An Act to Implement the Recommendations of the Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine” was introduced and signed into law by Governor Baldacci and became effective in July 2008. This law requires that when a newborn receives a newborn hearing screening result of “refer,” the facility that performed the screening schedule the newborn for a follow-up appointment with an audiologist.
- LD 2106 “An Act to Enhance the Newborn Hearing Program” was introduced and signed into law by Governor Baldacci and became effective in July 2008. This law allows the Maine Newborn Hearing Program to participate in a regional

database with the other New England states to share hearing screening, evaluation and intervention data for those children who did not receive those services in their birth state.

- Updated the Audiological Reporting Form in collaboration with the Maine Academy of Audiology and implemented its use starting March 1, 2008.
- Established a plan and protocols for contacting Primary Care Providers and families of those children who did not pass their newborn hearing screening and for whom the MNHP had not received a report on follow-up testing, evaluation, or diagnosis.
- Distributed over 20,000 copies of information materials to birthing facilities, health care providers, families, community agencies, and other interested parties.
- Created an EHDI State Plan created by the MNHP and key stakeholders who attended the 2008 National Early Hearing, Detection and Intervention Conference.
- MNHP Advisory Board met 4 times.
- Applied for HRSA and CDC funded grants.
- Conducted the Parent Feedback Survey for program evaluation.
- Sponsored a 2-day conference in collaboration with the Maine Academy of Audiologists which provided education, training and hands-on experience on current pediatric audiology practices.
- Sponsored a family support day for families of children with hearing loss.
- Helped organize a State of Maine Start-up chapter of Hands & Voices, a non-profit organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them.

Planned Activities for 2009

- Analyze CY2008 newborn hearing screening data.
- Continue to provide technical assistance to birthing facilities.
- Create a hearing screening training module for birthing facilities.
- Create an educational brochure on hearing screening which will be provided to prenatal classes as well as health care providers who offer obstetric services.

- Further evaluate the data and feedback from the Parent Survey and implement they key recommendations under the guidance of the Advisory Board.
- Work with MNHP stakeholders to refine and implement the EHDI State Plan that was created in 2008.
- Convene a task force to update the Pediatric Audiology Guidelines which were first established in 2003.
- Develop a plan to provide audiological testing and evaluation to rural locations in Maine on a quarterly basis.
- Finalize the MOA between the Department of Health and Human Services and the Department of Education addressing referrals to Child Development Services and follow-up early intervention services.
- Continue to work with the Maine Chapter of Hands & Voices to provide support, resources and education to families of children with hearing loss.
- Give a presentation on the importance of hearing screening, detection and early intervention to the Maine Chapter of the Academy of Pediatrics at their Spring 2009 Conference.
- Give a presentation to the Maine Chapter of Speech Language Pathologists on the importance of early intervention for infants at their Spring 2009 conference.
- Work with the Advisory Board to create culturally sensitive training on newborn hearing screening for health care interpreters and to evaluate the cultural sensitivity of the educational materials provided by the MNHP.