

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 CY2006, synthesizes Program activities for 2007 and activities for 2008. 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 and one full-time Office Assistant. 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. Both grant funds are available until June 2008 and August 2008 respectively. During 2008, there will be an opportunity to competitively apply for funding from both agencies.

Maine Newborn Hearing Program Advisory Board

The Maine Newborn Hearing Advisory Board was established to oversee the program and advise the MeCDC Director, Dr. Dora Anne Mills, MPS, on issues relating to the program and 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 September 2007 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 (32 hospitals and 1 free-standing birthing clinic) 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. During 2007 all of the thirty-three birthing facilities received a site visit with an in-service and technical assistance as appropriate.

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 123rd Maine State Legislature passing **P.L. 2007, Chapter 236 – An Act to Enhance the Newborn Screening Program.**

Newborn Hearing Screening Reportable Data CY2006

Data submitted during CY2006, to ChildLINK revealed that 14,009 births occurred in Maine. Of these, 13,539(96.7%) were screened for hearing loss, with 13,282 of those babies screened by one month of age. Of the 13,539 screened, 330 (2.4%) were referred for audiological evaluations. To date, we have received 113 (34.2%) reports on those babies who were referred. Ninety-three (82%) of the 113 babies for whom we received audiological evaluations were seen by 3 months of age. Of the 113 reports we have received, 14 babies were identified with hearing loss. We have received no Individual Family Service Plan (IFSP) information from Child Development Services

(CDS) in 2006. 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 CY2006 18 birthing facilities had a greater than 98% screening rate with five of these facilities obtaining a 100% rate. Only two facilities had less than a 95% screening rate. The remaining 13 facilities had screening rates between 95% and 98%. It is unlikely that all 33 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 2007

- Conducted site visits and provided technical assistance to all 33 birthing facilities.
- LD 1142 “An Act to Enhance the Newborn Hearing Screening Program” was introduced and signed into law by Governor Baldacci, and became effective September 21, 2007. This bill mandates that all providers of hearing diagnostic procedures report the results of their evaluation and diagnoses to the MNHP.
- 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, became effective June 27, 2007. In 2008, this task force will 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.
- Updated the Audiological Reporting Form in collaboration with the Maine Academy of Audiology.
- Established a collaborative partnership between Child Development Services and Early Childhood and Family Services (ECFS), part of the Maine Educational Center for the Deaf and Hard of Hearing. At the end of the first quarter of CY2007, the ECFS Program was providing early intervention services for 48 children birth to three years of age.

- Updated and mailed the listing of audiologists with expertise in newborn hearing testing to 1,200 health care providers that included primary care, birthing facilities, audiologists, and early intervention services.
- Published “Resource Guide for Families of Children with Hearing Loss,” “Resource Guide for Families with Mild Hearing Loss,” and “Resource Guide for Families of Children with Unilateral Hearing Loss.”
- Distributed over 20,000 copies of information materials to birthing facilities, health care providers, families, community agencies, and other interested parties.
- MNHP Advisory Board met 3 times. The MNHP Advisory Board is scheduled to meet 4/year but the December 2007 meeting was canceled due to a snow storm.
- Hired a Parent Liaison

Planned Activities for 2008

- Analyze CY2007 newborn hearing screening data.
- Continue to provide technical assistance to birthing facilities
- Apply for HRSA and CDC funded grants
- Implement the updated Audiology Reporting Form.
- Work with the “Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine” to meet the goals established by the Legislature.
- 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.