

Grant Number: H61MC0081

Project Title: Reducing Loss to Follow-up in Maryland After Failure to Pass Newborn Hearing Screening

Organization Name: Maryland Department of Health and Mental Hygiene

Mailing Address: 201 W. Preston St., Room 423, Baltimore, MD 21201-2301

Primary Contact Information: Tanya D. Green, Program Chief

Phone Number: 410.767.6432

Email Address: tanya.green@maryland.gov

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Performance Narrative

INTRODUCTION

The overall goal of this project is to reduce the number of Maryland infants who are lost to follow-up/lost to documentation (LTF/LTD) following a missed or failed newborn hearing screen. This project focuses on complete and comprehensive reporting and timely follow-up; improving accessibility to services; increasing stakeholder involvement; and facilitating greater inter-agency collaboration.

This project aims to reduce Maryland's LTF/LTD rate by addressing the barriers of access to services, compliance with data reporting, and coordination of care between providers and agencies. Outreach and education for families and providers, along with collaborative efforts among state agencies is being used to ensure follow-up services are accessible, completed and reported in a timely manner.

ACCOMPLISHMENTS:

The program's ability to follow up on babies needing follow up hearing screening and diagnostic testing improved with the hiring of a second follow up coordinator. The new coordinator is extremely efficient and is a good fit for the program. Parent involvement in many aspects of the program has increased. HRSA award funds allowed two parents to attend the 2013 National EHDI Meeting in Arizona. Both parents expressed their gratitude for the opportunity to attend. They provided feedback to the MD EHDI program about ideas they would like to see incorporated in our state, such as the use of tele-intervention for families who live in remote areas of the state, spreading the EHDI message to foster parents, and Deaf mentoring. One parent stated that she left the meeting feeling encouraged about the opportunities that lie ahead for her child. Additionally, one MD EHDI staff member was able to attend the National EHDI Meeting using HRSA award funds, and two staff attended using funding from another source. Parents have also actively participated in the NICHQ (National Initiative for Children's Quality) Learning Collaborative, providing valuable input to promote positive changes which can be spread from a small population, to populations statewide. Through a HRSA grant sub-award to a non-profit organization, "Parent Connections" was established. "Parent Connections" allows parents to serve as mentors, assisting families who have a child or children with hearing loss. Parents have assisted with the planning of the annual state EHDI stakeholders meeting and they actively participate on the state Hearing Advisory Council.

The Maryland NICHQ Learning Collaborative Team consists of the EHDI Coordinator, EHDI Program Audiologist, Title V Specialist, hospital audiologist, director of newborn hearing screening programs for five Maryland hospitals, early intervention provider, family support & resource center coordinator, and parents who have a child with hearing loss. Through the collaborative, the team has learned to aim for improvements through small tests of change that can be evaluated and improved upon before spreading statewide. By the end of the collaborative, MD EHDI aims to improve the quality, timeliness and documentation of diagnostic hearing evaluation, identification of permanent hearing loss, and enrollment into early intervention services. This will be done by increasing the percentage of audiologists reporting to MD EHDI, increasing the percentage of infants who undergo a diagnostic audiologic evaluation that have their evaluation results shared with MD EHDI, and increasing the percentage of infants who are identified to have permanent hearing loss and are documented as being enrolled into early intervention services by 6 months of age. An audiology practice was targeted as a test case to increase provider reporting to MD EHDI. Previous efforts to accomplish this had been unsuccessful. A letter was emailed to the practice which contained praise for the practice and an invitation to providers to learn about the MD EHDI database. This effort was successful and now will be spread to other practices within the state.

BARRIERS:

During the current project period the program has faced barriers to purchasing hearing screening and diagnostic equipment as a result in staff turnover and staff shortage in the department's fiscal department. There were also barriers to participation in the NICHQ that were related to acquiring and retaining committed partners.

STRATEGIES TAKEN TO OVERCOME BARRIERS:

New staff was hired in the fiscal department which is expected to lead to a reduction in delays to procurement processes. Initially it was difficult to recruit and retain audiologists and early intervention providers to actively and continually participate in the NICHQ Learning Collaborative. With continued and varied outreach efforts, interested and committed audiology and early intervention partners have been vital contributors.

GOALS AND OBJECTIVES:

Overall Measure: Percent of Maryland infants who are lost to follow-up/lost to documentation following a missed or failed newborn hearing screening.

Goal 1: To increase the number of timely referrals to follow-up of infants who fail or miss their newborn hearing screening.

Measures:

- 1.1 The percent of IHP follow-up cases that have documented initial contact by 2 weeks.
- 1.2 The percent of IHP follow-up cases that have documented second contact by 4 weeks.
- 1.3 The percent of IHP follow-up cases that have documented second contact by 6 weeks.

Objectives:

1. Hire to fill vacant follow-up coordinator position within Project Year 1.
2. Increase the number of timely contacts with the parents and care providers (primary care doctor, audiologists, or other associated providers) of infants **who miss** their newborn hearing screening throughout the entire project.
3. Increase the number of timely contacts with the parents and care providers (primary care doctor, audiologists, or other associated providers) of infants **who fail** their newborn hearing screening throughout entire project.

Progress:

During Project Year 1, the hiring freeze was lifted to allow for the hiring of a second follow-up coordinator. There were two rounds of interviews and subsequently the position was filled by a well-qualified individual on 02/01/2012. However, the employee worked for one month and suddenly resigned to move out of state. A new hiring freeze exemption was requested and approved. During Project Year 2, a second follow-up coordinator was hired on 09/26/2012.

Statistical data was obtained by querying the MD EHDI database to determine the number of babies for which the data system provided the appropriate reminder alert to indicate the need for follow up action. Follow up action is taken at 2, 4, and 6 weeks post discharge. An analysis of the data revealed system limitations of which the database vendor has been made aware and is working toward resolution. The percentages obtained in the data reflected cases in which a scheduled appointment was pending, and these are cases which would not receive follow up contact until after the scheduled appointment or if the family did not keep the scheduled appointment. The database vendor is working on a solution that will allow extraction of this data without including pending appointments. It was also discovered that there were some instances in which the data system was not automatically disabling the alert that notifies the follow up coordinators that an infant has completed the screening phase. In some of these cases the alert was manually disabled, but the data is reflecting many cases that it should not be counting. Lastly, a non-data system related issue is that follow up coordinators were sending follow up letters but not documenting the action in the database. The follow up coordinators have received training regarding how to document their actions in the database. Once the database has been upgraded, improved data quality will allow for an accurate analysis of the timeliness of follow-up of infants who fail or miss their newborn hearing screening.

Goal 2: To increase family/parent involvement in all aspects of the MD EHDI program.

Measures:

- 2.1 The degree to which MD EHDI program ensures family/parent participation in its program and policy activities.
- 2.2 The number of events that included parent participants.
- 2.3 The number of individual parents who participated in MD EHDI in any way within a designated time period.

Objectives:

1. Create a plan for parent involvement in developing and implementing MD EHDI policies and programs within one month of project award notification.
2. Design and implement parent outreach, network, education and training through a sub-grant award to a parent organization within the first quarter of Project Year 1.
3. Ensure parent participation in Maryland's national level EHDI activities.

Progress:

At the beginning of the project period, a sub-grant award entitled, "Parent Outreach, Education and Training Activities," was provided to the Parents' Place of Maryland (PPMD) to create a plan for parent involvement in the MD EHDI program. The Parents' Place is a non-profit organization that provides peer support and other services to families of children with any kind of disability or special health care need. It serves as both Maryland's Family Voices and F2F (Family to Family) federal grantee. A parent liaison was hired through the sub-grant award to facilitate program activities under the parent involvement plan. The "Parent Connections" parent to parent mentor program for families of children with hearing loss was launched in May, 2012 and a plan for parent-outreach, networking, and educational activities was implemented.

"Parent Connections" has 9 mentors and 15 total parent matches. Mentors have received leadership and mentoring training. Mentors plan and organize regional parent training. Some topics during this reporting period include, "Welcoming Winter with Your Deaf or Hard of Hearing Child," A brochure has been developed and approximately 1,600 brochures have been disseminated to pediatricians, otolaryngologists, neurologists, parents, audiologists, speech-language pathologists, teachers, infant and toddler programs, hospitals, and the Maryland School for the Deaf. The program is being promoted through presentations, displays and site visits to a variety of audiences: parent meetings, council meetings, local colleges, and hospitals. The program was featured in an article the January, 2013 issue of "Baltimore Child's Magazine," www.baltimoreschild.com.

Parents were actively involved in the planning of the 2013 annual Maryland EHDI Stakeholders meeting which was held on May 16, 2013. Speakers included Howard Rosenblum, Chief Executive Officer, National Association of the Deaf, Peter Hausner, Ph.D. Director, Deaf Studies Laboratory, Rochester Institute of Technology, Diego Preciado, M.D., Ph.D., Associate Professor of Surgery, Pediatrics, and Systems Biology, George Washington University, and Carolyn Quattrocki, Executive Director, Governor's Office of Health Care Reform. Updates were provided on the "Parent Connections" and Maryland EHDI programs. There were 73 attendees. The meeting was successful as indicated by many positive evaluations submitted by participants (44 completed evaluation forms were turned in). Attendees included members from the Deaf community, parents, educators, physicians, community health care providers, and administrators.

HRSA grant funds were used to send two parents and one MD EHDI staff member to the 2013 National EHDI Meeting. A third parent received an NCHAM stipend to attend the meeting.

Two additional MD EHDI staff members received funding to attend the meeting through a separate federal funding opportunity.

Goal 3: To improve access to outpatient infant hearing screening services for parents in targeted, high-need areas or populations of the state.

Measure:

- 3.1 The percent of infants within each identified jurisdiction that need and receive an outpatient infant hearing screening.

Objectives:

1. Identify jurisdictions and/or populations of greatest need for outpatient screening services prior to the start of Project Years 1 and 2.
2. Purchase Otoacoustic Emissions (OAE) screening equipment within the first quarter of each Project Year.
3. Create outpatient infant hearing screening sites within highest need jurisdictions or populations within the first quarter of each Project Year.
4. Promote use of newly created outpatient hearing screening sites by the end of the third quarter of each Project Year and throughout entire Project period.
5. Monitor newly created outpatient hearing screening sites to ensure access and use by families requiring outpatient services at time of award and throughout the third quarter of each Project Year.

Progress:

During Project Year 1, Western Maryland was chosen as the initial target for outpatient screening services with selected sites to receive OAE equipment as an incentive to serve populations in the area, and Southern Maryland was identified as another area of high need to be addressed. However, during the beginning of Project Year 2, a follow up assessment of Maryland's underserved areas for hearing screening and diagnostic follow-up revealed that the numbers of babies needing follow-up in those areas were historically low. Results from a subsequent needs assessment indicated that the following sites would benefit from the equipment and also expressed willingness to receive and utilize the equipment: OAE units to Special Beginnings Birthing Center and Bay Area Midwifery and ABR (Auditory Brainstem Response)/OAE combination units to Carroll County Health Department, Washington County Health Department and the Maryland School for the Deaf.

Purchase of the equipment was not made during Project Years 1 or 2 due to delays caused by state procurement procedures. It is desired that a carryover request will be granted and that the plan to purchase the equipment will move forward in the upcoming project year.

Goal 4: To establish a system for maternity center and home-based midwives to report occurrent infant births to MD EHDI.

Measure:

- 4.1 The percent of maternity center and home births reported to MD EHDI.

Objectives:

1. Educate maternity center and home birth midwives on the MD EHDI processes within the third quarter of Project Year 1.
2. Establish a reporting relationship with Maryland maternity center and home birth midwives within the fourth quarter of Project Year 1 and throughout the remainder of the project period.
3. Promote the practice of infant hearing screening by maternity center and home birth midwives throughout Project years 2 and 3.

Progress:

Educational outreach has been extended in the form of site visits to the two birthing centers in Maryland, Special Beginnings Birthing Center and Bay Area Midwifery to teach them about the Maryland Early Hearing Detection and Intervention purpose and procedures. Training on the MD EHDI database has been provided to the staff at both birthing centers. The staff has been very receptive to working directly with MD EHDI. Special Beginnings has expressed interest in conducting follow up hearing screens if funding would be provided for the screening equipment.

Goal 5: To increase provider participation within the MD EHDI program.

Measure:

- 5.1. The annual LTF/LTD rates of individual practitioners and/or practices who have attended educational sessions or received site visits.

Objectives:

1. Obtain certification to provide Continuation Medical Education (CME) credits for physicians and Continuing Education Units (CEU) for audiologists within the first quarter of Project Year 2.
2. Increase contact with PCPs and/or other physicians, and audiologists by the end of the fourth quarter of each Project Years 2 and 3.

Progress:

There are currently three physician practices that consistently report to the state using the MD EHDI database. Practice 1 has been reporting since April, 2012 and has a LTF rate of 0 (18 cases completed and 1 May, 2013 baby in process). Practice 2 has been reporting since October, 2012 and has a LTF rate of 0 (238 cases completed, 1 June, 2013 and 2 May, 2013, and 1 April,

2013 babies in process). Practice 3 has been reporting since January, 2013 and has a LTF rate of 0 (18 cases completed and 1 June and 2 May babies in process).

The Maryland EHDI AAP Chapter Champion has been active in her efforts to encourage the use of the MD EHDI database by Maryland's physicians and to spread the message of early hearing detection and intervention and reducing loss to follow up. Outreach has included site visits and speaking engagements and the creation of an EHDI section on the state's AAP website: <http://www.mdaap.org/EHDI%20webpage.html>. The following articles were published in the MD AAP Newsletter:

Volume 6, Issue 4

<http://www.mdaap.org/Nov%202011%203.pdf>

- Early Hearing Detection and Intervention (EHDI) In Maryland
- History of the Maryland EHDI Program

Volume 6, Issue 5

http://www.mdaap.org/AAPNews_Spring2012final.pdf

- The Maryland Infant Hearing Screening Database Facilitates Timely Follow Up, Intervention and Documentation

Volume 6, Issue 6

http://www.mdaap.org/AAPNews_July2012-%20FINAL.pdf

- New Resource for the Families of Children who are Deaf or Hard of Hearing

Volume 6, Issue 7

http://www.mdaap.org/AAPNews_Oct2012.pdf

Congenital CMV, Hearing Loss and the Role of the Pediatrician

Goal 6: To develop a long-term action plan for MD EHDI and MD EHDI that is responsive to the needs of the population served.

Measure:

- 6.1. The percent of identified activities completed under this goal.

Objectives:

1. Conduct a comprehensive appraisal of the entire MD EHDI process within the first quarter of Project Year 3.
2. Develop a long-term action plan for incorporating the needs identified by the appraisal to form the basis for the future work of MD EHDI within the fourth quarter of Project Year.

Progress:

This activity will be conducted during Project Year 3.

SIGNIFICANT CHANGES:

A second follow-up coordinator was hired on 09/26/2012. Leah Washington's resume is included as attachment 2.

PLANS FOR UPCOMING BUDGET YEAR:

In the upcoming budget year, plans are to purchase and disseminate equipment to the previously selected provider sites for follow up hearing screening or diagnostic testing. Training will be provided to staff in the use of the awarded equipment. Information will be disseminated to families in need of services about the new screening and diagnostic sites. Provider practice staff will receive training on how to report outpatient infant hearing screening results using the MD EHDI online reporting database. Monthly tracking of reports received from each new site will be conducted to ensure site usage and reporting compliance. MD EHDI will continue to provide and expand upon educational outreach opportunities to the midwife community. The Chapter Champion will finalize training and educational webinars which will be posted on the MD AAP website. CME (Continuing Medical Education) Units will be offered. Parents will continue to assist with the planning of the annual state EHDI stakeholders meeting. The next meeting will be held in May, 2014. NICHQ quality improvement methods will continue to be incorporated into the permanent fabric of the program. Poster sessions will be planned for the next Maryland Academy of Audiology and Maryland Academy of Pediatrics meetings.

APPENDICES:

Attachment 1 – Estimated Unobligated Balance

Attachment 2 – biosketch for new personnel: Leah Washington