

*Maryland Department of Health and Mental Hygiene
Office for Genetics and Children with Special Healthcare Needs
Infant Hearing Program*

**ONLINE DATA MANAGEMENT TO REDUCE LOSS TO FOLLOW-UP AFTER
FAILURE TO PASS NEWBORN HEARING SCREENING**

Program Narrative

#H61MC00081

Continuation Grant, 2009-2010

Summary

The long term goal of this project is to ensure that all Maryland babies born deaf or hard of hearing receive timely and appropriate follow-up in order to achieve their communication potential. Review of the Infant Hearing Program's previous years' statistics revealed significant issues with data collection and analysis. An inadequate data base severely hampered abilities to analyze trends and identify weaknesses and deficiencies in the newborn hearing screening program; therefore, the decision was made to implement a new online data management system. As a result of the state RFP process, an online system and vendor was selected with the anticipation of full implementation into the Maryland birth hospitals by October 2008. The implementation and utilization of this new system is the focus of this project with the following goals in mind:

1. Increase result reporting
2. Decrease reporting errors
3. Improve timeliness of test result availability
4. Facilitate continuity of care and tracking of follow up care
5. Identify factors influencing loss to follow up
6. Decrease the number of initial screening failures who do not return for rescreens by one month of age
7. Decrease the number of second level screening failures that do not receive timely diagnostic audiologic evaluation
8. Increase the number of children diagnosed as deaf or hard of hearing with early intervention outcomes
9. Utilization of the online system for diagnostic result reporting by all the State's pediatric audiologists

In the first year of the project the new system was fully implemented into all of the Maryland birth hospitals. 100% of the hospitals are reporting hearing screening results into the online data system. Screening results are available now in real time as opposed to 3-5 days after screening to all providers identified as being involved in the baby's hearing healthcare as well as to the Infant Hearing Program at the Department of Health and Mental Hygiene. The rate of babies receiving follow up screening by one month of age increased 5%, but the rate for diagnostic evaluations by 6 months decreased

approximately 10%. However, it should be noted that data from the new system is only available for 8 months therefore many of those infants needing diagnostic evaluations are still in process. A more accurate assessment of the loss to follow up will be available once the system has been operational for at least a year.

No data is yet available on the number of infants receiving early intervention services. Although an MOU has been drafted, it has not been finalized and the data sharing between the Maryland Department of Education and the Maryland Infant Hearing Program is in process.

Utilization of the electronic reporting by the State's pediatric audiologists remains a work in progress. Currently approximately 50% of the reporting audiologists have been trained in the use of the online system. There is no legal mandate for the reporting of diagnostic evaluations in Maryland; therefore, reporting by audiologists is completely voluntary.

Progress to Date

Goal 1: Improve data management through installation of the eSP online data management system:

Beginning June 2008, trainings were held at each of the 36 Maryland birth hospitals and by September 2009 all the hospitals' screening staff were trained, data managers identified, secure usernames and passwords assigned, and all hearing screening data was being entered into the online data system, eSP. Previously, hearing screening data had been collected on the blood spot card and entered into the State Lab data base by lab staff and then transferred to the Infant Hearing data base. Abandoning this old system and moving to an online system was quite a procedure departure for the hospitals; therefore, extensive training plans were developed. Plans made prior to the training to overcome anticipated issues included:

1. Detailed manuals for managers and 'cookbook' style flip chart manuals for user quick reference.
2. Professional presentations to hospital screening staff on the EHDI process with emphasis on supporting research and parent testimony.
3. 24/7 technical support from the vendor, email and phone support from the Infant Hearing staff available 6:30-5:30 Monday through Friday
4. Monthly online user meetings.

However, there were significant barriers that we naively had not planned for that threatened the project. Although all hospitals had internet access, not all screening staff had access to a computer or had IT rights to access the internet. Additionally, many IT departments were claiming that the online data management system was a HIPAA violation.

With the help of our vendor, Oz Systems, federal and state privacy regulations were reviewed with hospital and IT administrators and now 100% of the hospitals are reporting screening results electronically and more than 80% utilize direct importing of demographic information from their hospital's admission data base into eSP. The direct

importing of demographics reduces the errors that can occur with manual data entry and improves our ability to access families for follow up.

State legislation requires not only that birth hospitals provide hearing screening, but results have to be reported to the Department of Health and Mental Hygiene, (DHMH), in a format chosen by the DHMH. All hospitals were provided with copies of the legislation and meetings were held with nursery and IT managers to review the requirements and rationale. Although this required additional time and effort that had not been originally allotted for, the meetings, phone calls, and correspondence yielded positive outcomes and 100% compliance with the new reporting procedure. All Maryland hospitals have been reporting all hearing screening results electronically since August 2008.

An online virtual training was developed for the audiologist users. The live version of the training was held at 3 different times on 3 different days to accommodate a variety of schedules. Approximately 15 audiologists tuned in for the first live virtual training. The training was recorded and available upon request for audiologists unable to attend. Since the initial virtual training, 27 audiologists have undergone the training via the recorded training session and established secure access to eSP.

Goal 2: Increase result reporting, decrease reporting errors, and improve timeliness of test results availability.

In an effort to reduce human data entry error, the eSP data base allows for direct data importing from the hospital's admissions data base directly into eSP. Prior to the initial trainings contact was made with all hospital screening managers and IT managers. The demographic import procedure was outlined and information was provided regarding file transfer requirements with the anticipated hopes that by the time screener training commenced that their systems would be set up and ready to go. However, resistance was encountered at all the hospitals from the IT departments. Most cited work load issues and reported that developing the file necessary was a low priority. We did not want to slow the implementation process down, so training was given on both manual demographic data entry and electronic data entry with the hopes that hospitals would see the time savings in electronic importing and pressure would be brought to bear by the appropriate in-house administrators. This was the case for the first 15 hospitals, but the remaining 21 hospitals required some additional coaxing. By setting new deadlines for demographic importing for those non-compliant hospitals and contacting each of the hospital's IT and screening managers both by email and by phone, within 2 months time, another 14 more hospitals were directly importing demographic information. More than 80% of the hospitals are now performing direct demographic importing into eSP. The remaining 20%, have extensive entire computer system revamping projects already in process and are unable to address any new electronic issues until next year. To be certain that all births are being entered into eSP, those hospitals not doing direct importing are required to forward daily census to Infant Hearing so that manual review can be made of those sites to ensure that no baby was not entered into the system.

Goal 3: Facilitate continuity of care and appropriate tracking and follow up through the cascade of care.

The objective was to train hospital screening staff and outpatient providers on the eSP online data management system by October 2008. Live train the trainer sessions were held across the state for all 36 birth hospitals from June through July 2008. By August, 2008 all hospitals were trained and utilizing eSP to report all of their hearing screening results. In the following year, requests will be made to the hospitals to provide the Infant Hearing Program with birth certificate lists so that comparisons can be made with the birth records in eSP to ensure that all births are in the system.

Goal 4: Identify factors influencing loss to follow up of infants that do not pass or miss newborn hearing screening.

Monthly compliance reports are compiled and shared with each birthing hospital. The reports provide both numbers and percentages as well as scores on predetermined metrics. The five metrics included: percent of infants screened, percent of babies that pass, percent of NICU infants without hearing screening results entered in eSP, percent of records with contact information included, and the percent of infant records with an identified PCP. Hospitals were given scores of meeting compliance, distinguished compliance or non-compliance based on the following criteria:

METRIC	STANDARD COMPLIANCE	DISTINGUISHED COMPLIANCE
% Screened	95% of all births	98% of all births
% Pass	90% of all screenings	95% of all screenings
% NICU in process	<20% of all NICU births	<10% of all NICU births
% with contact info	95%	99%
% with PCP	95%	99%

Compliance rates for the hospitals in 2008 are illustrated below:

METRIC	AVERAGE PERCENTAGE	RANGE
% Screened	94.2%	93.1-95.2%
% Pass	95.6%	95-96%
% NICU in process	20.9%	19.6-22.6%
% with contact info	94.8%	90.9-96.9%
% with PCP identified	68.2%	66.9-79.3%

Standards were intentionally set high, and in all areas except identification of a medical home, the hospitals eventually met the standard or exceeded it. Review of 2009 compliance reports reveals steady improvement in all areas, and as of April, 2009 the average for identification of a medical home has increased to 78% with half (18) of the hospitals having met or exceeded the standard of 95%.

A stakeholders meeting is to be scheduled for the later part of this reporting year. These findings will be reported and a plan for improvement will be developed.

Goal 5: Decrease the number of initial screening failures who do not return for rescreens by one month of age.

The objective is to develop revised procedures as a result of data analysis that improve recording of family demographics, and identification of the infant's medical home to facilitate timely and accurate follow-up. The monthly compliance reporting, as discussed previously, has yielded significant improvements at the individual hospitals. This process will continue on an on-going basis, but capturing the audience of outpatient providers that are not hospital based requires a more involved strategy.

Evaluation of existing resources to support the outpatient providers revealed an out of date outpatient provider directory and state Screening Guidelines. To update these critical documents a work group consisting of pediatric audiologists, hospital screening personnel, and Infant Hearing staff, has been formed to update and expand the current Maryland Screening Guidelines. An outline for the updated guidelines was agreed upon and initial work has begun. New areas to be included in the document will be: frequently used terms, universal precautions, expanded personnel information, screener training and re-training, and equipment explanations and maintenance recommendations. Much needed updates will be made to incorporate the JCIH 2007 best practices and new reporting procedures. The group will convene again throughout the summer with anticipation of the guidelines being completed by December 2009. The provider directory has been updated and will be reviewed at the upcoming "1-3-6 The Formula for Successful Diagnosis and Referral of Infants with Hearing Loss" meeting on June 18, 2009. Additional input will be sought at the Infant Hearing Stakeholders Meeting in August 2009. The new directory and guidelines will be posted on the Infant Hearing website once they are completed.

Goal 6: Decrease the number of rescreen failures who do not receive timely diagnostic audiologic assessments.

In Maryland, diagnostic result reporting is not mandated by legislation; thus, diagnostic reporting to the Maryland Infant Hearing Program is accomplished only through the goodwill of the audiologists and the referral assistance of the medical home. To support this objective, communication processes have been initiated through newsletters, professional presentations at the Maryland Academy of Audiology, the Maryland Speech and Hearing Association, the Family Support conference, hospital grand rounds, and Towson University and University of Maryland speech and hearing department lectures to reach the audiologist and pediatric provider communities and encourage their involvement in the EHDI process. Training efforts will continue with the online audiologist's training program.

Work with the medical home community has been severely hampered by the lack of a chapter champion. The Maryland Academy of Pediatrics as well as the American Academy of Pediatrics have both been contacted, but they have been unsuccessful in

recruiting a physician to the position. Efforts will continue to reach out to the pediatrician community through the Universal Newborn Hearing Screening Advisory Council and the emeritus members of the Maryland Academy of Pediatrics. Meanwhile, the Infant Hearing Program will collaborate with the Maryland Medical Home Initiative to raise awareness of the needs of infants with hearing loss.

Goal 7: Increase the number of children diagnosed as deaf or hard of hearing into appropriate, culturally sensitive early intervention by 6 months of age.

After struggling for years to share data between the Maryland Department of Health and Mental Hygiene (DHMH) Infant Hearing Program and the Maryland State Department of Education (MSDE) so that comprehensive outcome assessment can be completed and that assurance can be made that all infants identified with hearing loss are receiving appropriate intervention, a Memorandum of Understanding is being developed between the two agencies. It has not been finalized by the MSDE due to delays in the IDEA and OSEP regulations and the recent loss of the key Part C person who served as liaison with the DHMH Infant Hearing Program and who was involved directly in this process. However, preliminary processes have been designed to actually facilitate the sharing of data, but at this point they are only rudimentary and temporary. It is our intention to expand the online data system to include an early intervention module that would enable both agencies access to the appropriate data.

Current Staffing

The Maryland Infant Hearing Program has been fortunate enough to be fully staffed for the last two years. Current staff includes two audiologists, Linda Vaughan and Erin Filippone, two special program coordinators, Stephanie Hood and Theresa Thompson, and one administrative assistant, Hope Wharton. The audiologists both have lengthy clinical and pediatric experience and have been a part of the MD EHDI team for 3+ years. The special program coordinators have several years of experience in public healthcare, care coordination, and patient follow up. Both coordinators have been a part of the team for several years and bring solid experience in early hearing detection and intervention. The special program coordinators provide tracking and follow up for infants that are missed or do not pass their inpatient hearing screening. The program audiologist tracks the hearing screenings of infants that do not pass their second hearing screening to ensure appropriate diagnostic follow up and early intervention referral. The audiologists provide technical and programmatic support to MD EHDI. Linda Vaughan serves as the director and provides administrative oversight, program development, personnel and budget management, and liaison with the Program's collaborative partners, community agencies, and allied professionals.

Technical Assistance Needs

MD EHDI has elected to focus intense efforts on the technical aspects of hearing screening tracking and surveillance. The addition of the online data management system, while an expensive, time consuming project, has already proven to have numerous benefits. However, there are limitations to the data base and the Infant Hearing Program

is seeking funding for data enhancements through the Centers for Disease Control. Funding is being requested to configure an early intervention module of eSP in order to track and monitor referral and enrollment status of children with hearing loss in the state of Maryland. An aggregate reporting feature to the EI module will be programmed to allow users to see how many referrals and enrollments are present and/or needed. The second report to be added is an aging report to provide analysis of the age at which referrals and enrollments were provided to children in Maryland. Programming enhancements will be made to improve the tracking of at risk infants, reducing duplications, and logic changes that will improve statistical analysis.

Unmet need continues to be the availability of diagnostic pediatric facilities. Parts of the state have no audiology referral sites and parents are forced to bring their babies to the larger urban centers such as Baltimore and Washington D.C.. Remote auditory brainstem response testing appears to be the best solution, whereas an ABR unit would be rotated to the various areas of the state that are not served and testing would be completed by an audiologist in a distant urban center via telehealth networks. However, the practical aspects of funding and initiating this type of technical, as well as service, program are significant. Funding for expensive items such as an ABR unit may be available, but even if the funds are available, procurement procedures in Maryland and the Department of Health and Mental Hygiene are so protracted that expending the funds within the grant period is nearly impossible. Still, the Infant Hearing Program administrators are committed to this goal, and efforts will be made to make this type of program a reality.

Technical Linkages

Currently, there are no direct links between the eSP data base and other State health departments data bases, even though this type of linkage would prove invaluable both in coordination of follow up and evaluation of prevalence and incidence, socio-economic and demographic impacts, service delivery needs, and care coordination. Departments and agencies within the State are shiloed and very program specific. Development and integration of databases occurs in isolation which makes after-the-fact data sharing linkage costly and labor intensive. That being said, plans are being formulated to develop file sharing relationships with Vital Statistics, and the Maryland State Department of Education Infants and Toddler Program,

Collaborative Partners

Early hearing detection and identification could not be carried out without the assistance of our partners in MD EHDI. The Infant Hearing Program at DHMH teams with a multidisciplinary advisory council, 36 birthing hospitals, 1 children's hospital, 2 pediatric rehabilitation hospitals, 100+ outpatient hearing screening and audiology facilities, more than 3,000 pediatricians and family practitioners, the Maryland Infant and Toddler Program, and our data base vendor OZ Systems to fulfill the goals of early identification and intervention of deaf and hard of hearing infants.

The Infant Hearing Program has established collaborative relationships with the Maryland Department of Education, the Maryland School for the Deaf, the Hearing and Speech Agency, Parents Place, and the Maryland Infant Toddler Program to develop professional and family training, consumer information products, and interagency data sharing. Through grants from the Department of Health and Mental Hygiene, workshops for families and early interventionists and other related professionals have been provided at least annually. Additional grants have funded the Maryland Keys to Communication notebooks for families of deaf and hard of hearing infants, as well as other consumer and professional brochures used for communication between providers and families. Each year the Infant Hearing Program hosts a stakeholder meeting for all involved in infant hearing including hospital providers, physicians, nurses, early interventionists, families, and audiologists. The stakeholders meeting is an opportunity for inter-agency communication, collaboration, and learning.

MD EHDI is dedicated to hearing screening and early intervention for all babies born in Maryland. Because of its size and geographic location, there are a number of babies that are born in Maryland but reside in another state. To ensure that these 'border babies' receive appropriate follow up a report is sent on an as needed basis to our border states' EHDI Programs regarding births and screening status of babies born in Maryland but residing in Pennsylvania, Washington D.C., West Virginia, Virginia, or Delaware.