

**PENNSYLVANIA DEPARTMENT OF HEALTH
UNIVERSAL NEWBORN HEARING SCREENING GRANT
NARRATIVE PROGRESS REPORT**

TABLE OF CONTENTS

1) Experiences to Date	1
2) Significant Changes	7
3) Collaboration and Coordination	8
4) Significant Findings	9
5) Data Requirements	10
6) Response to Conditions/Recommendations from MCHB	12
7) Plans for the Upcoming Budget Year	12

Attachments:

- Attachment A - Ms. Mary King-Maxey Resume**
- Attachment B - Bureau of Family Health Organization Chart**
- Attachment C - Division of Newborn Screening and Genetics Organizational Chart**
- Attachment D - Dr. James Zeigler**
- Attachment E - Infant Hearing Screening Advisory Committee Table**

This report details achievements for the Universal Newborn Hearing Screening Grant (number H61MC00097) during the period September 1, 2007 through August 31, 2008. Also included are plans for the upcoming year starting September 1, 2008 through August 31, 2009.

1) Experiences to Date

A) Brief Summary of Overall Project Accomplishments

The Universal Newborn Hearing Screening and Intervention Program (UNHSI) is housed in the Pennsylvania Department of Health's (DOH) Bureau of Family Health (BFH), which also administers Pennsylvania's Title V, Maternal and Child Health Block Grant (MCHBG) including programs for children with special health care needs.

All of the state's 114 hospitals with a birthing center report hearing screening results to DOH and refer the names of newborns not passing a follow-up screening when necessary; and/or, names of those failing to keep a scheduled follow-up screening appointment. DOH's Nurse Consultants engage in active follow-up for all infants referred and follow each case to conclusion. Follow-up activities include telephone contact, e-mail, facsimile and written correspondence with hospitals, families, primary care physicians (PCPs), audiologists, and Early Intervention (EI) providers.

When initiating follow-up for individual infants, the Nurse Consultants send an informational letter to parents notifying them of the need for a re-screening or diagnostic evaluation, the importance of getting the testing and encouragement to communicate results with the DOH. A copy of this letter is sent to the identified PCP for the infant. Once the first communication is sent by certified mail, the Nurse Consultants attempt to contact the parents by phone and confirm with each PCP that the individual is indeed their patient. In many cases, the PCP is incorrectly identified on the initial referral causing delays in follow-up. Parents expressing the need for medical coverage are referred to Medicaid, which is administered by the PA Department of Public Welfare, or to the Children's Health Insurance Program (CHIP), which is administered by the PA Insurance Department (PID). The Nurse Consultants make extensive use of the PA Language Line to communicate with parents that are non-English speakers, and the PA Relay Line to communicate with persons that are deaf or hard-of-hearing. Referrals are tracked to conclusion at logical endpoints within the 1-3-6-month Universal Newborn Hearing Screening and Intervention process queue. Community Health Nurses in DOH's six District Offices and county and municipal health departments assist with follow-up activities and make home visits to locate families.

In January 2008, DOH submitted the 2006 Early Hearing Detection and Intervention survey report to the Centers for Disease Control and Prevention (this survey provides a basic summary of data for infants born between January 1, 2006 to December 31, 2006 including the number and percent of infants screened for hearing loss, diagnosed with hearing loss, and enrolled in early intervention). DOH follow-up activities for these

newborns occurred well into calendar year 2007. Select data and highlights for DOH follow-up activities included in this report are:

- a. 141,791 newborns completed hearing screening (95.48% of all births for calendar year 2006).
- b. DOH received 1,400 referrals from hospitals and midwives for follow-up.
- c. From the 1,400 referrals,
 - (1) 638 infants received a diagnostic audiological test and were diagnosed with normal hearing.
 - (2) 274 infants received a diagnostic audiological test and of those:
 - (a) 143 were diagnosed with a permanent hearing loss
 - (b) 131 infants were diagnosed with a non-permanent hearing loss
 - (c) 127 of the infants diagnosed with permanent hearing loss were documented as being linked with early intervention services.
- d. Using the method established by the Centers for Disease Control and Prevention to calculate Loss to Follow-up/Loss to Documentation, the calculated loss to follow-up/loss to documentation rate for the 1,400 referrals was only 21% compared to national figures.

DOH was an active participant in the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative Project, sponsored by the Health Resources and Services Administration (NICHQ is an action oriented organization dedicated solely to improving the quality of health care provided to children). By working through the Medical Home this effort seeks to improve short and long term outcomes for infants with hearing loss and their families. The focus was to improve Newborn Hearing Screening systems of care for follow-up by targeting specific steps in the process including screening, diagnosis, referral to early intervention, entry into appropriate care and connection of every identified infant to an appropriate Medical Home. Specific accomplishments to-date are:

- a. The PA team modified initial letters sent to parents for hearing screening referrals to improve reading level and health literacy. The letters included information on next steps in the hearing screening process and various contact information to encourage communication with the DOH. The team also created a hearing screening roadmap, outlining the stages and expectation of each step in the hearing screening process as well as direct referral information for Early Intervention. The roadmap is included with each initial contact letter to families. A separate similar letter, to the primary care physician, is currently in the user acceptance testing phase.
- b. The team revised the DOH Hearing Screening form to include alternate contact information for the family. This revised form was tested in two hospitals in June and July, 2007. There was a 100% success rate in contacting these families who provided alternate contact information. These revisions will be incorporated into the referral form.

- c. The PA NICHQ team designed an audiological brochure for primary care physicians in Northeastern Pennsylvania. The brochure's purpose was to aid physicians in making appropriate referrals to facilities that provided hearing screening services for infants. These brochures were distributed to several practices.
- d. The PA NICHQ team designed an audiological brochure for parents in Northeastern Pennsylvania. The brochure's purpose was to assist parents in learning about different testing techniques available for their babies and provided information about facilities in their area available to conduct those tests. This brochure inspired the beginning of a directory of audiologist that is in the development stages.

Each year approximately 3,400 births in Pennsylvania occur outside of a hospital. In calendar year 2003, using statistical data provided by the Department's Bureau of Health Statistics and Research, UNHSI program staff analyzed the distribution and concentration of Out-of-Hospital (OOH) births to identify areas of need. Over the past several years DOH has purchased portable hearing screening units with funding from state and federal UNHSI grants. Free-standing birthing centers and midwives received training on use of the screening units. After the training, free-standing birthing centers and midwives sign an agreement to use the equipment on a shared basis, to submit screening data to DOH monthly, and to make referrals to the UNHSI program for infants who do not pass hearing screening. There are currently 20 machines in rotation.

B) Progress on Specific Goals and Objectives

Program Goal 1: Statewide implementation of a comprehensive newborn screening web-based reporting and tracking system.

Objective 1.1: Provide a statewide web-based reporting and tracking system for DOH, birthing hospitals, audiologists, primary care physicians, and midwives.

Objective 1.2: Create an integrated electronic child profile record for all newborns that contains relevant contact, demographic, metabolic and hearing screening information.

Objective 1.3: Provide capability to generate customized reports for policy-making, quality assurance, program evaluation, and decision support.

Objective 1.4: Establish electronic communications with birthing hospitals, audiologists, PCPs and midwives.

Update on Program Goal 1: In an effort to enhance the existing Newborn Screening Data System and make it available to birthing hospitals, audiologists, primary care physicians and midwives, on March 19-20, 2007, the Division of Newborn Screening and Genetics Program hosted a Health Resources and Services Administration (HRSA) Newborn Screening Data Systems Review. The HRSA team participants included Dr. Brad Therrell - National Newborn Screening and Genetics Resource Center, Dr. Marie Mann - Project Officer for

HRSA, Dr. Fred Lorey - California Department of Health and Ms. Ellen Amore - Rhode Island Department of Health. The recommendation of the review team was that the current data system has deficiencies that will be difficult to resolve and has numerous limitations such as adding expanded newborn screening conditions. The review supported DOH's decision for a Request for Quote (RFQ) to evaluate commercial off-the-shelf newborn screening systems to replace the current web-based newborn screening system.

The RFQ selected vendor began working with DOH staff in the spring of 2007 and completed their tasks in December 2007. Deliverables included a business requirements document, gap analysis and cost evaluation of several Commercial Off the Shelf systems as well as the existing system. Negotiations with the selected vendor to purchase a data system have begun.

Program Goal 2: Link all infants with a hearing loss to an effective medical home.

Objective 2.1: Increase the number of newborn hearing screening referrals to DOH that have the correctly identified medical home (MH) from 50% to 90%.

Objective 2.2: Achieve coordinated efforts between PCPs and audiologists to improve follow-up care services for infants and their families.

Objective 2.3: Provide technical assistance to birthing hospitals, audiologists and PCPs.

Update on Program Goal 2: On May 24, 2007 DOH entered into a new contract with the Pennsylvania Chapter for the American Academy of Pediatrics (PA AAP). The deliverables in that contract that deal with Program Goal 2 are:

- PA AAP will provide educational outreach to hospitals, primary care physicians and audiologists through its EPIC-EHDI program to maximize the number of infants identified with hearing loss by ensuring that they receive hearing screening by one month of age, diagnostic evaluation by a pediatric audiologist no later than three months of age, and early intervention services by six months of age.
- PA AAP will be working with hospitals and primary care physicians to create best practice guidelines for communicating the results of every newborn's hearing screening to the correct primary care physician in a timely manner. Six pediatric practices have begun collecting data on newborns seen in the hospital by a primary care provider who is not a member of the practice. Practice staff will track when the hearing screening results are received from the hospital. This information, along with ideas collected from hospitals that are successfully communicating and reporting hearing screening results will be used in a pilot program and then published as guidelines for all hospitals to use.
- PA AAP will also be presenting to primary care physician groups to educate and reinforce the goals of the EHDI program. A pediatrician, who has a child with hearing loss and is a member of the state Infant Hearing Screening Advisory Committee, will be presenting at the annual Pennsylvania Osteopathic Medical

Association meeting on May 2, 2008 to review the importance of newborn hearing screening, the goals of an effective EHDI program, and the primary care physician's role in the medical home and in monitoring all children's hearing ability during health visits.

- PA AAP will continue enhancing the online continuing education website, known as ONLI-EHDI. The list of resources for physicians and parents has been updated and many additional resources have been added. Two new case studies will enhance primary care physicians' knowledge of newborn hearing loss and the role a primary care physician plays in providing timely referrals to audiologists, appropriate specialists and early intervention services as well as counseling families of a child diagnosed with hearing loss. The new cases will take an in-depth look at: 1) a NICU patient with auditory neuropathy; and 2) an infant who passes newborn hearing screening but whose parents express concerns with the child's hearing at the 4-month visit. A 4-color insert to promote the ONLI-EHDI website is included with the DOH notification letters mailed to primary care physicians who have been identified as caring for an infant who did not pass his/her hearing screen.
- PA AAP also provides technical assistance to hospitals, primary care physicians and audiologists as directed by DOH. During the current grant year technical assistance has been provided to assist hospitals in the selection of new hearing screening equipment and to improve timely communication of follow-up hearing screening results to DOH.
- As an important step in ensuring that all infants identified with a potential hearing loss receive a diagnostic evaluation by 3 months of age, the PA AAP will work with DOH and Early Intervention Technical Assistance (EITA)/Pennsylvania Training and Technical Assistance Network (PaTTAN) to compile a list of pediatric audiologists in Pennsylvania and communicate this list to primary care physicians. The two contractors are developing a pediatric audiologist survey that will be mailed to all licensed audiologists in the state later this year. The list of pediatric audiologists will be mailed to all family practices and pediatric practices in the state and will be made available on the ONLI-EHDI website.
- To ensure that a child with a diagnosed hearing loss receives all the proper services needed, a care plan will be developed to identify the roles and responsibilities of the primary care provider, audiologist, early intervention providers, and other specialists who are part of the medical home. A group of medical professionals, EHDI providers and parents will meet later this year to draft a care plan. This care plan will be sent out to providers in the state for comments and the final version will be communicated by mail and website.

Program Goal 3: Infants identified with a hearing loss will receive appropriate Early

Intervention services before 6 months of age.

Objective 3.1: Build the professional skills of Part C Early Intervention providers.

Objective 3.2: Provide newborn hearing screening technical assistance to service coordinators and Part C Early Intervention providers.

Update on Program Goal 3: DOH has a new contract with EITA (Early Intervention Technical Assistance) which is a part of the Pennsylvania Training and Technical Assistance Network (Pa TTAN). The deliverables in the contract that deal with Program Goal 3 are:

- a. EITA has developed and will present a series of trainings to Part C-Early Intervention providers and others that focuses on ensuring appropriate linkage to Early Intervention services consistent with the unique needs of each child, family preferences for treatment, and the utilization of local resources to meet the needs of the family as a whole. They are scheduled for May 6-8 and May 13-15, 2008 in Harrisburg, Wilkes-Barre, King of Prussia, Erie, Altoona and Pittsburgh (one in each DOH district). Emphasis will be placed on developing an understanding of all communication modes and options so that choices can be explained to families in an unbiased manner. At least one of these sessions will be videotaped for later training
- b. EITA is monitoring the Part C, Early Intervention caseload contained in the Department of Public Welfare, Early Intervention Reporting System (EIRS) for infants identified as having hearing loss or deafness. EITA will begin to provide to DOH the number of children entering the Early Intervention system with a hearing loss, their age of referral, geographic distribution of referrals, the number of children exiting the system/or no longer in need of services, and the intervention stay times. A ten percent representative sample will be selected and more detailed information will be collected for sampled children, including whether these children passed newborn hearing screening, the children's use of amplification and/or cochlear implants, their ages at diagnoses of hearing loss, types and severities of hearing loss, hearing status of their parents, presence/absence of multiple disabilities and the communication mode(s) chosen by their families. This information will assist the DOH in assessing the EHDI system of service.

Program Goal 4: Families of young children with a confirmed hearing loss will have access to a support system and appropriate information.

Objective 4.1: Provide support and appropriate information to families of young children with a confirmed hearing loss.

Update on Program Goal 4: DOH has a new contract with EITA (Early Intervention Technical Assistance) which is a part of the Pennsylvania Training and Technical Assistance Network (Pa TTAN). The deliverables in the contract that deal with Program Goal 4 are:

- a. EITA will design and distribute a satisfaction survey for families of children with hearing loss enrolled in Early Intervention services. The survey will be used to assess whether parents were informed about the full range of communication options and linked with appropriate services and supports and satisfied with the Early Intervention process.
- b. EITA will use the results of this survey to prepare a parent resource guide that illustrates communication modalities, Early Intervention services, and family support options available.

PA AAP and members of the Infant Hearing Screening Advisory Committee developed a parent resource brochure. *World of Opportunity: A Guide for Families of Children with Hearing Loss*, brochure includes family-friendly information on hearing loss, the importance of early identification, medical assistance, Early Intervention, and contact information for national/local resources. With funding from DOH, forty-thousand copies were printed and thirty-five-thousand of those copies were mailed to family practitioners, physicians and audiologists.

The DOH is in the development stages of providing mini-grant opportunities for community organizations to begin or continue parent support groups for families of children with hearing loss. An evaluation component is required for these grant recipients to determine effectiveness of the support group.

C) Barriers and Strategies Utilized to Overcome Them

The Family Educational Rights and Privacy Act (FERPA) and Part C privacy laws remain challenging in developing data interchange capability between the Department of Public Welfare's Early Intervention data system and the web-based UNHSI follow-up tracking system. Therefore, the new UNHSI system will not have the capability for automated confirmation of EI enrollment after diagnosis of hearing loss. Until interagency discussions yield a solution, DOH follow-up staff continues to rely on parents, PCPs, and audiologists to confirm EI linkages. The possibility of a comprehensive consent form for families and Memorandum of Understanding between the Department of Public Welfare, Education and Health are under consideration. As previously mentioned, EITA will monitor specific information in the Early Intervention Reporting System (EIRS). In addition, EITA will select a ten percent representative sample with more detailed information for the sample children including: whether these children passed newborn hearing screening, the children's use of amplification and/or cochlear implants, their ages at diagnoses of hearing loss, types and severities of hearing loss, hearing status of their parents, presence/absence of multiple disabilities and the communication mode(s) chosen by their families.

2) Significant Personnel Changes

A) Key Staff Changes

Mr. Robert F. Staver, the Hereditary and Hearing Services Section Manager and the Universal Newborn Hearing Screening Program Grant Manager transferred out of the

Department of Health on May 11, 2007. Mr. Arthur A. Florio immediately assumed the role as Acting Universal Newborn Hearing Screening Program Grant Manager until September 17, 2007. Mr. Florio's experience as the Program Administrator of the Newborn Hearing Screening Program for the previous three years provided a seamless transition. Ms. Mary King-Maxey joined the staff as the new Program Grant Manager for Universal Newborn Hearing Screening Program (see Attachment B – Ms. King-Maxey's resume). Ms. King-Maxey has served the Department for eleven years and as a Program Administrator for our Health and Human Services Call Center for five years. Her experience in managing large projects and data systems has proven valuable to the program.

B) Key Advisory Committee Changes

Pennsylvania's six-member Infant Hearing Screening Advisory Committee continued its active involvement in program development and general oversight. In the summer of 2007, the Secretary of Health appointed James Zeigler, PhD to the committee to fill a member's expired term. Dr. Zeigler is an audiologist in private practice. Additional stakeholder representatives also contributed expertise from hospital, Early Intervention service provider, and parent advocate perspectives (see Attachment G - A descriptive table listing of Advisory Committee members).

3) Collaboration and Coordination

The state UNHSI program continues to coordinate efforts with other programs and state agencies addressing children with special health care needs, including the Title V Maternal and Child Health Block Grant recipient as well as other Department of Health programs serving children with special health care needs, Department of Public Welfare, which administers both the state Medicaid program and the Part C, EI program; the Department of Education, which administers the Part B, EI program; the PA Department of Insurance, which administers the Children's Health Insurance Program (CHIP); and the Department of Labor and Industry Office of the Deaf and Hard of Hearing. As in the previous year, program staff assisted in the delivery of a major outreach presentation at the state convention of the Pennsylvania Chapter of the American Academy of Audiologists in order to apprise private practice audiologists of the latest UNHSI program developments. The UNHSI Program Administrator now serves as the Department of Health's designated representative to the State Advisory Council for the Deaf and Hard of Hearing, which is housed in the Pennsylvania Department of Labor and Industry's Office of Vocational Rehabilitation.

Other current and planned methods of collaboration and coordination include:

- a. PA Chapter of the American Academy of Pediatrics will continue to carry out the EPIC-EHDI project, under contract with the state UNHSI program with federal funds from the UNHSI grant. DOH works in close collaboration with PA AAP to: develop cooperative relationships between physicians and audiologists, increase the quality

- and accuracy of screenings, communicate test results and stress the importance of early referral, diagnosis and linkage to EI.
- b. Pennsylvania Academy of Audiology is a Professional association representing many of the 700 audiologists licensed to practice in PA. The Academy is collaborating with PA AAP and DOH to develop coordinated effort between physicians and audiologists, and has been supportive of DOH's efforts.
 - c. PA Advisory Council for the Deaf and Hard of Hearing is Located in the PA Department of Labor and Industry's Office of Vocational Rehabilitation. The Council's mission is to advance the independence of persons with hearing loss and to support equal opportunity for deaf and hard of hearing persons. The Council fully supports DOH's UNHSI efforts, and a DOH representative participates as a member of the Council.
 - d. Independent County and Municipal Health Departments house Community health nurses in 10 cities and counties with their own health departments. These nurses conduct home visits for hard-to-contact cases in their jurisdictions that are followed by the UNHSI program. These efforts help to assure follow-up when infants miss outpatient re-screening or audiological diagnostic appointments, assist with high risk monitoring, and help families connect with parent support.
 - e. "Every Child Deserves a Medical Home" Initiative (MHI) is administered by the BFH Division of Community Systems Development & Outreach, and is a collaborative effort of DOH and the PA AAP. The UNHSI program staff has been meeting with the Medical Home program staff to begin sharing program information and exchange ideas to encourage joint messaging to participating physicians served.
 - f. Miscellaneous Partners working with the UNHSI Program include the following: Hospital Association of Pennsylvania; PA Speech Language Hearing Association; DPW's Office of Medical Assistance Programs (DPW/OMAP), which administers the state Medicaid Program, Department of Education, Educational Resources for Children with Hearing Loss, and Pennsylvania Insurance Department, which administers the state Children's Health Insurance (CHIP) program.

4) Significant Findings

All of the state's 114 hospitals with a birthing center report hearing screening results to DOH. UNHSI program staff conducted a review in 2006 and determined that a small number of hospitals accounted for a large percentage of losses to follow-up. Specifically, the review revealed that for 2005 calendar year births, eight hospitals with a birthing center accounted for approximately 45% of the losses to follow-up. UNHSI program staff discussed this review with members of the Infant Hearing Screening Advisory Committee. UNHSI agreed to offer these facilities state funds totaling \$250,000 to purchase newborn hearing screening equipment or diagnostic audiological equipment; or to purchase brochures, audio visual equipment, videos or related supplies or materials for birth education programs or to increase educational opportunities, to parents about the importance of newborn hearing screening and timely follow-up to identify early childhood hearing loss. All ten facilities receiving grant funds have agreed to provide the parents or guardians with the following information:

- a. The results of the screening - whether the newborn passed or did not pass the screening - and the interpretation of the results. The results are to be conveyed verbally and in writing to the parents using a standard notification form prepared explicitly for this purpose.
- b. If the infant does not pass the initial screening, the facility shall inform the parents of the importance of obtaining a follow-up re-screening as soon as possible, and shall schedule a return appointment for outpatient re-screening during the period from 14 to 30 calendar days following the infant's date of birth.
- c. If the initial screening was not completed due to the infant being transferred to a neonatal intensive care unit (NICU), the parents should be informed that the facility discharging the infant to home is responsible for performing the screening.
- d. The parents shall receive information on milestones of normal auditory, speech and language development in children.

5) Data Requirement

As shown in the following table, this narrative describes key findings of the program. UNHSI follow-up activities for newborns in calendar year 2006 occurred well into calendar year 2007. For births in calendar year 2006, 142,611 births (hospital and out-of-hospital combined) received initial screenings, out of the overall statewide number of occurrent births (148,505 – most recent preliminary count from the Department of Health's Bureau of Health Statistics).

- a. There were 914 documented refusals of screening among hospital and out-of-hospital births combined (less than 0.6% of all births).
- b. Of the 8,549 newborns not passing initial screening and in need of follow-up screening, a total of 7,729 (91.3%) received the follow-up screening.
- c. A total of 1,400 newborns did not pass the follow-up screening, meaning that a diagnostic audiological evaluation was needed.
 - a. Of these, 638 were found to have normal hearing
 - b. 274 were diagnosed with some form of hearing loss
 - c. There was no known diagnosis for 488 of the cases followed (34.9%). Of these, 8 infants expired, 44 moved out-of-state, there were 146 cases of services being declined by parents, and 290 (21%) were lost to follow-up/lost to documentation.

2006 Diagnostic Information		
DIAGNOSED WITH NORMAL HEARING		
Diagnosed With Normal Hearing Before 3 Months of Age	247	
Diagnosed With Normal Hearing Before 6 Months of Age	52	
Diagnosed With Normal Hearing After 6 Months of Age	28	
Diagnosed With Normal Hearing Age Unknown	311	
Subtotal Diagnosed With Normal Hearing		638
DIAGNOSED WITH PERMANENT HEARING LOSS		
Diagnosed With Permanent Hearing Loss Before 3 Months of Age	94	
Diagnosed With Permanent Hearing Loss Before 6 Months of Age	32	
Diagnosed With Permanent Hearing Loss After 6 Months of Age	17	
Diagnosed With Permanent Loss Hearing Age Unknown	0	
Subtotal Diagnosed With Permanent Hearing Loss		143
DIAGNOSED WITH NON-PERMANENT CONDUCTIVE HEARING LOSS		

For the 127 infants diagnosed with permanent hearing loss and documented as being linked with early intervention services, 102 were enrolled with EI before 6 months of age; 23 were enrolled after 6 months of age but before twelve months of age; 2 were enrolled after twelve months of age.

Follow-up outcomes for infants referred to the UNHSI Program between calendar years 2004 and 2006 have shown the number of infants identified with a hearing loss have stabilized. Those numbers are displayed in the following chart.

Comparison 2004-2006 Births	
2006 Births (final)	148,505
Diagnosed with some form of hearing loss	274
% Diagnosed with hearing loss	0.18%
2005 Births (final)	144,948
Diagnosed with some form of hearing loss	256
% Diagnosed with hearing loss	0.18%
2004 Births (final)	144,499
Diagnosed with some form of hearing loss	181
% Diagnosed with hearing loss	0.13%

6) Response to Conditions/Recommendations from MCHB

- A)** Go further in developing newborn hearing screening systems to respond to OOH births.

During the current project year federal UNHSI grant funds will be used to maintain all 20 portable hearing screening units in rotation. Currently UNHSI program staff are reviewing the feasibility of replacing some older machines with state funding. Local/regional equipment loan networks have been established in 18 primarily Amish and Mennonite communities containing the highest concentrations of OOH births in the state. In calendar year 2006, 1,189 OOH newborns completed hearing screening representing approximately 31.6% of all OOH births in the state. The program goal is to screen up to 60% of the state’s approximately 3,500 OOH births that occur annually. Prior to starting each local screening network, participating midwives receive training from a manufacturer’s representative followed by competency training at a cooperating hospital under the oversight of the hospital’s UNHSI nurse manager or at a home gathering of midwives with an audiologist present. After the training, midwives sign an agreement to use the equipment on a shared basis, to submit screening data to DOH on a monthly basis and to make referrals to the UNHSI program for infants not passing hearing screening.

- B)** Address the issue of informed consent.

DOH continues to advise hospitals to review their procedures related to patient data and parental consent to enable them to obtain and report follow-up information in accordance with HIPAA privacy requirements. DOH has issued a HIPAA policy statement for distribution to healthcare professionals upon request explaining its legal opinion that no HIPAA violation exists when disclosure of patient newborn

hearing screening information is made to DOH, since the purpose of such disclosures is to promote treatment.

- C) The applicant should assure that audiologist training includes Visual Reinforcement Audiometry (VRA) proficiency.

DOH's UNHSI program did not sponsor any training this year. However, VRA proficiency will be included in any future training.

7) Plans for the Upcoming Budget Year

A) Continue working with the PA Chapter of the American Academy of Pediatrics.

Major planned activities for the upcoming year with PA AAP include:

- a. PA AAP will work will be working with hospitals and primary care physicians to create best practice guidelines for communicating the results of every newborn's hearing screening to the correct primary care physician in a timely manner with the Pennsylvania Academy of Audiology to identify pediatric audiologists qualified to provide complete hearing diagnosis and pediatric amplification services and to communicate this information to both primary care providers and families of children with suspected/diagnosed hearing loss. The two organizations also plan to develop strategies to work collaboratively on assuring that children with hearing loss receive referrals to Early Intervention and that families are given consistent messages about communication options and the need for Early Intervention.
- b. PA AAP will also be presenting to primary care physician groups to educate and reinforce the goals of the EHDI program
- c. PA AAP will collaborate with Early Intervention Technical Assistance (EITA) to build a resource list of audiological services across Pennsylvania. EITA will identify audiologists providing EI services via service providers and case documentation in the Early Intervention Reporting System (EIRS).
- d. PA AAP will provide technical assistance as needed to birthing hospitals that receive a letter from DOH regarding their low screening and/or referral rates. In addition, for primary care practices identified by DOH as poorly compliant in referring babies for diagnostic testing and/or early intervention services, the PA AAP will offer ongoing assistance and education regarding the need for early referral and diagnosis.

B) Continue working with EITA/PaTTAN.

Planned activities and deliverables are described above in Update to Program Goal 4.

C) State-wide hospital/midwife workshop.

Using state funds, DOH plans to offer state-wide teleconference workshops for hospital staff working in the newborn hearing screening program, midwives who screen newborns in the Out-of-Hospital Newborn Hearing Screening Program and others. The purpose of the workshops are to increase screening accuracy and quality by conveying best practice and quality assurance information and provide UNHSI program updates, screening techniques and suggestions.

D) Presentation before the statewide Academy of Audiology Convention

In September 2008, a representative from the PA Chapter of the American Academy of Pediatrics will present before the Pennsylvania Academy of Audiology state-wide convention on Pennsylvania's Newborn Hearing Screening Program. In the presentation, the representative will review the importance of newborn hearing screening and discuss the elements of an ideal program. Also included in the presentation are the planned activities to identify pediatric audiologists qualified to provide complete hearing diagnosis and pediatric amplification services and methods to communicate this information to both primary care providers and families of children with suspected/diagnosed hearing loss.

E) Family Support

UNHSI program staff, members of the Infant Hearing Screening Advisory Committee and others have begun to collect information and discuss methods to support the establishment of a newborn/infant hearing screening family support organization in Pennsylvania. Ms. Erin Champion, a member of the Infant Hearing Screening Advisory Committee and the parent of two young hard-of-hearing children, has been selected to coordinate this effort. Ms. Champion attended the 2008 Early Hearing Detection & Intervention Conference held February 25-26, 2008 in New Orleans, Louisiana as the parent representative for the UNHSI Program and attended the 4th annual Hands & Voices Leadership Conference in Lyons, Colorado in July 2007 as well as the EHDI Family Support Conference in October 2007.