

## **I. Project Identifier Information**

- a. Grant Number: H61MC24882
- b. Project Title: Universal Newborn Hearing Screening and Intervention
- c. Organization Name: Pennsylvania Department of Health
- d. Mailing Address: Commonwealth of Pennsylvania; 625 Forster Street; Harrisburg, PA 17120-0701
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## **II. Accomplishments and Barriers**

HRSA newborn hearing screening carry over grant funds were used during this reporting period to purchase eight new portable OAE hearing screening units for free-standing birthing centers and midwives. All locations received hands-on training in the use and care of the equipment from an experienced pediatric audiologist. Initial feed-back from the free-standing birthing centers and midwives has been very positive. Screeners report that the new equipment is much easier to use and screening results are obtained faster than with the aABR equipment used previously. The introduction of new OAE equipment and the removal of older aABR equipment will also reduce ongoing program costs for supplies and disposables.

Updates and enhancements to the PA EHDI website ([www.paearlyhearing.org](http://www.paearlyhearing.org)) were undertaken in late 2012 and early 2013. A “Frequently Asked Questions” section for families, physicians, audiologists and hospitals was added to the website. At the April 2013 annual EHDI meeting in Glendale, Arizona the PA EHDI website received an award for continued excellence in EHDI website design and presentation.

In February 2013 the state EHDI program launched a hospital pilot project for electronic reporting in the new OZ eSP system. Three hospitals are participating in the pilot project and several others plan to join. All three hospitals are submitting newborn hearing screening results for all newborns tested and the EHDI program is beginning to use the information for both follow-up and performance monitoring.

In November 2012 the EHDI program and PA Guide By Your Side entered into an agreement that allows for direct referral of parents from the EHDI program to PA Guide By Your Side. The PA Guide By Your Side Program has also entered into an agreement with Children’s Hospital of Philadelphia that allows for direct referrals of parents from the Audiology Department at the hospital to the PA Guide By Your Side Program. At this time of this writing, the PA Guide By Your Side Program has enrolled 105 families.

As a significant barrier, all state funding to the EHDI program was eliminated in fiscal year 2011-2012. The program has received no state funding since then. The current administration is focusing resources on direct care to the public and is moving away from infrastructure building, education and prevention programs. At this time the Title V

Maternal and Child Health Block Grant provides support to the EHDI program by paying for staff salaries and certain administrative costs; however, because of the recent federal sequestration, MCH Block Grant funding has been reduced. At this time, it is uncertain how the reduction in federal funding will impact the state EHDI program.

### **III. Goals and Objectives**

#### **1. Goal: Reduce the number of infants lost to follow-up after initial screening.**

1.1. Objective: Provide technical assistance and quality improvement programs to hospitals that demonstrate high lost to follow-up rates.

- a. Identify birth hospitals with high loss to follow-up rates by reviewing hospital monthly reports.
- b. Review hospital monthly reports and compare failed screen numbers to referral numbers, refer for technical assistance when discrepancy indicated.
- c. Implement quality improvement program in hospital newborn hearing screening programs.
- d. Document and distribute best practice suggestions from hospital quality improvement programs.

#### **ACCOMPLISHMENTS:**

In Pennsylvania hospital newborn hearing screening programs must submit monthly newborn hearing screening reports to the state EHDI program. The reports contain aggregate information on the number of births and hearing screening outcomes. All reports are reviewed by the EHDI program administrator. Any reports that contain obvious errors are set aside and the program administrator contacts the hospital for clarification. Information for all reports is then entered into an electronic database. Performance data for all hospitals is then tracked over time to measure hospital screening performance, referral rates, trends and averages. Quarterly and yearly summary performance reports are produced for all hospitals and then shared with the PA Infant Hearing Screening Advisory Committee members, key stakeholders and PA AAP representatives.

From a review of the performance reports, onsite technical assistance visits are made to hospitals identified as needing improvement. Professional staff from PA AAP coordinates the onsite visits with a team that includes a neonatologist, a pediatric audiologist and the EHDI program administrator. During the visits the team will review the hospital's newborn hearing screening performance with hospital staff to improve performance across the following 4 metrics: reducing the number of newborns not screened because of family refusal; reducing the number of newborns not screened because hospital staff did not perform the screen prior to discharge; correcting a hearing screening fail rate that is too high or too low; and, identifying and tracking babies lost after a failed hearing screen

and improving the effectiveness of hospital staff at bringing these babies back for a follow-up rescreen.

Five hospitals had onsite visits during this reporting period. With the assistance of the other visit team members, after each onsite visit, Dr. Robert Cicco, MD and pediatric advisor to the EHDI program, writes a report summarizing each onsite visit, including strengths and recommendations for improvement. This report is then provided to the hospital's newborn hearing screening coordinator. Phone meetings were conducted 60 days following each visit to follow-up on recommendations.

1.2. Objective: Develop and share best practices with hospital workgroup and provide opportunity for input on policy issues.

- a. Maintain hospital workgroup through regular email communications and quarterly conference calls.
- b. Document and distribute best practice suggestions from hospital workgroup.

#### ACCOMPLISHMENTS:

A hospital work group teleconference was held on September 20, 2012. The focus of this call was, "An Overview of the Pennsylvania Newborn Hearing Screening Program". The presenters were Dr. Robert Cicco and Arthur Florio, the EHDI program administrator. Information was presented on the role of hospitals in the newborn hearing screening program.

A hospital work group teleconference was held on January 9, 2013. The focus of this call was how the Pennsylvania newborn hearing screening program is working from a parent's perspective. The parent presenters for this workshop were Ms. Hadley Haas, the parent representative on the Pennsylvania Department of Health's Newborn Hearing Screening Advisory Committee. Ms. Haas has two young children with hearing loss. Ms. Anne Gaspich was the second presenter. Ms. Gaspich is the Program Coordinator for Pennsylvania's Guide By Your Side Program and works with 105 families who have infants who have been identified with hearing loss. Ms. Gaspich described her family's story as they moved through newborn hearing screening, diagnosis, treatment and Early Intervention.

A hospital work group teleconference was held on April 24, 2013. The topic for this call was, "Lessons Learned and Best Practices from Hospital Onsite Visits". The presenters were Dr. Robert Cicco from PA AAP and Arthur Florio, the EHDI program administrator. During the teleconference Dr. Cicco and Mr. Florio summarized best practices identified during ten hospital onsite visits. A draft best practice document was shared with the work group. Representatives from nineteen hospitals participated in the teleconference.

## 2. Goal: Reduce the number of infants lost to follow-up after second screening.

2.1. Objective: Improve communications with PCP office.

- a. Provide educational information about Online-EHDI web-based training to PCPs through PA AAP newsletters and copies of patient letters.

### ACCOMPLISHMENTS:

Through a partnership between the state EHDI program and the University of Pittsburgh Center for Continuing Education in the Health Sciences, the On-Line EHDI website provides continuing education to PCPs on newborn hearing screening and early childhood hearing loss. During this reporting period, the On-Line EHDI website has been updated. There are now 6 online courses that use a case-based format: healthy newborn who does not pass newborn hearing screening; child with profound hearing loss; baby with persistent middle ear effusion; child with unilateral hearing loss; bilateral neural hearing loss; and, late onset bilateral progressive Sensorineural hearing loss.

Courses can be selected individually and completed for 0.5 CME credits each. PA AAP maintains On-Line EHDI with assistance from the University of Pittsburgh Center for Continuing Education in the Health Sciences and promotes this training via the PA EHDI website and through articles in the PA AAP E-News, a monthly newsletter that is sent to 2,100 pediatricians across Pennsylvania.

2.2. Objective: Provide educational opportunities to PCPs on the hearing screening process and early childhood hearing loss.

- a. Host an annual teleconference on hearing screening issues and early childhood hearing loss.
- b. Provide web-based training and free CMEs on hearing screening case studies and diagnostic protocols.

### ACCOMPLISHMENTS:

A webinar/teleconference was held on June 5, 2013. The topic presented was, "*Hearing Assessment after the Newborn Period – Understanding the Importance and Increasing Effectiveness*". The presenter was Sara McKay, AuD, Children's Hospital Philadelphia.

2.3. Objective: Improve education, communications and coordination between families, PCPs, audiologists, Hospitals and DOH to ensure continuity of care.

- a. Market the PA EHDI Website to user groups.

### ACCOMPLISHMENTS:

A rack-card is used to advertise the PA EHDI website. The rack-card is routinely distributed electronically by the EHDI program administrator to hospitals, audiologists and others. Hard copies of the rack card are distributed at workshops and meetings. Finally, information on the PA EHDI website is included in all EHDI program mailings to parents, primary care physicians and audiologists.

2.4. Objective: Improve PCP referrals to audiologists.

- a. Track current patterns of referral to audiologists by PCPs.
- b. Assess ability of diagnostic centers and audiology practices.
- c. Determine referral quality issues of children diagnosed with late onset hearing loss or mild hearing loss later in childhood.

ACCOMPLISHMENTS:

At the November 30, 2012 Infant Hearing Screening Advisory Committee meeting, Dr. Robert Cicco informed the Committee that he and Dr. David Chi, an Assistant Professor in Otolaryngology at the University of Pittsburgh School Of Medicine, have been working with the EHDI program to develop a project to look at children identified with permanent childhood hearing loss after the newborn period. Dr. Cicco briefly discussed a paper on this subject that had recently been presented by Dr. Chi at The American Society of Clinical Oncology meeting. Dr. Chi's paper is titled, "*Children with Sensorineural Hearing Loss after Passing Newborn Hearing Screen*". Dr. Cicco is making arrangements for Dr. Chi to present this paper at a future Advisory Committee meeting.

**3. Goal Enhance the existing out-of-hospital birth hearing screening program.**

- 3.1. Objective: Provide assistance and support to the existing out-of-hospital birth hearing screening network.
  - a. Onsite visits to 10 midwife networks each year.
- 3.2. Objective: Conduct yearly midwife "refresher" training.

ACCOMPLISHMENTS:

During the fall and winter of 2012, eight new Otodynamics Otocheck OAE hearing screening units were placed at midwife networks. These units replaced old aABR equipment. All midwife networks that received the new equipment also received "refresher" training. The instructor for the refresher training was Dr. Sherman Lord, a pediatric audiologist who is familiar with the new equipment and with newborn hearing screening. During the training Dr. Lord covered how to care for and maintain the equipment; and, did hands on refresher training in the use of the equipment. Several midwife networks attended each training session so that midwife screeners from different networks could share information on screening protocols and techniques. These refresher trainings will be repeated yearly.

**4. Improve the services and supports provided by Early Intervention to infants and toddlers who are deaf/hard of hearing and their families.**

- 4.1. Objective: Provide a range of statewide professional development activities for Early Intervention service coordinators, providers and administrators to improve the quality of Early Intervention services for infants and toddlers with hearing loss and their families.
- a. Provide educational workshops to enhance the skills of service coordinators and other Early Intervention providers serving children with hearing loss and their families.
  - b. Provide parent scholarships to statewide annual Low Incidence Institutes
  - c. Create web-based training courses based on the educational workshops and other relevant topics.

**ACCOMPLISHMENTS:**

In December 2012 a state-wide workshop entitled, “Early Visual Language and Visual Learning in Infants and Children who are Deaf or Hard of Hearing” was presented by Sharon Baker, EdD. Participants learned about new and emerging research supporting the early use of American Sign Language (ASL), fingerspelling, and other forms of visual communication. They also received information and strategies for improving children’s language outcomes. Current beliefs and attitudes about Deaf Education (including Early Intervention) were explored and compared with preliminary findings from a national longitudinal study. Each participant received a draft copy of a new assessment tool: Deaf & Hard of Hearing Children’s Visual Communication & Sign Language Milestones. The workshop was recorded and posted on the Early Intervention website and will be used in future trainings.

To encourage parents with infants and toddlers to attend educational workshops, the EHDI program and the state Early Intervention program have supported parent scholarships to the annual Pennsylvania Low Incidence Institutes that take place in State College, PA. The first two days of these institutes, called Great Start, include workshops specifically targeting support for infants and young children with deafness or hearing loss and their families; Great Start includes many nationally and internationally well-known researchers and clinicians as speakers. Over the last 6 years, approximately 15 parent scholarships each year have been distributed to all the families who applied.

- 4.2. Objective: Provide a range of resources and materials to improve Early Intervention services and supports.
- a. Provide educational resources through Short Term Loan Kits.
  - b. Develop and implement a statewide FM loaner system.
  - c. Update the publication for families “Getting Started” that is required to be given to each family of a child with hearing loss.

#### ACCOMPLISHMENTS:

Through the Short Term Loan Kit program supported by this grant, Early Intervention has been able to provide curricula and materials on a loan basis to EI service providers who work with infants and toddlers with deafness/hearing loss and their families. During the current year, these materials were reviewed and updated to ensure that Early Intervention providers and families have access to current resources that they can use on a loan basis and consider for their own purchase. Feedback from users was analyzed to determine if modifications to the loan system were necessary.

A limited bank of FM systems suitable for infants and toddlers with hearing aids has been acquired as part of current grant activities. The development of a customized FM Loaner Bank is being piloted and evaluated. The FM Loaner Bank is receiving technical support from a pediatric audiologist associated with the PA EHDI program.

- 4.3. Objective: Update, implement and analyze an annual statewide parent satisfaction survey.
- a. Conduct parent satisfaction survey annually.
  - b. Analyze and share survey results in presentations to Department of Health Newborn Hearing Screening Advisory Group, State Interagency Coordinating Council for Early Intervention and other state groups.

#### ACCOMPLISHMENTS:

Three-hundred and fifty-two surveys were distributed by the state Early Intervention program in January 2013. One hundred and six surveys were returned for a response rate of 30%. The survey results were presented by Early Intervention staff at the May 10, 2013 Infant Hearing Screening Advisory Committee meeting. Results are also being shared with ERCHL (Education and Resources for Children with Hearing Loss); OCDEL (Office of Child Development and Early Learning); and, the state Interagency Coordinating Council.

- 4.4. Objective: Utilize the state Early Intervention Data system to compare information with the Department of Health in both retrospective and quarterly comparisons.
- a. Utilizing data on children with dates of birth beginning in 2009, compare annual numbers of infants with hearing loss identified by Department of Health with those with Early Intervention records.
  - b. Using quarterly data from the Early Intervention Statewide Data system compare infants with hearing loss entering Early Intervention with numbers of children identified by the Newborn Hearing Screening program.

#### ACCOMPLISHMENTS:

The EHDI program and the state Early Intervention program began to exchange non-identifiable data on newborn and infants during the past year. At the November 30, 2012

Infant Hearing Screening Advisory Committee meeting, Stacy Antoniadis, M.A. CCC/SLP, M.P.H, Consultant with the PA Training and Technical Assistance (PaTTAN) Network, discussed this exchange of data between the two programs. Ms. Antoniadis presented data for 2010 and 2011 newborns that were identified by the EHDI program and data for those same years on the number of children enrolled in EI with an Individual Service Plan indicating that the children were receiving services for hearing loss. The EHDI program and Early Intervention continue to examine methods to share data that would benefit both programs.

## **5. Implement and evaluate the family support program Hands and Voices Guide By Your Side of Pennsylvania.**

- 5.1. Objective: Reduce the number of infants lost to follow up by having trained Parent Guides assist in follow up.
- a. Provide unbiased information and support to interested families.
  - b. Provide outreach to hospitals, agencies and programs.
  - c. Provide a Guided Family Notebook to all families who receive GBYS services and a Care Coordination Binder.
  - d. Evaluate the program.

### **ACCOMPLISHMENTS:**

Since the inception of PA GBYS in November 2011 one-hundred and five families have been enrolled in the program. In November 2012 Tuscarora Intermediate Unit #11, the fiscal agent for PA GBYS, and the Department of Health initiated a “Business Partner Agreement” that allows PA GBYS to receive the names and contact information of families whose infants did not pass Newborn Hearing Screening program and were subsequently diagnosed with hearing loss. This “direct referral” will greatly increase the number of families participating in the program.

## **IV. Significant Changes:**

The Division of Newborn Screening and Genetics consisted of three sections: The Newborn Screening and Follow-Up Program; the Newborn Hearing Screening Program; and the Genetics Section. These sections developed out of specific pieces of legislation requiring the Department of Health to develop and implement programs to serve these populations. Over the years, the number of conditions followed by the Department has increased significantly as we follow the lead of the Secretary's Advisory Committee on Heritable Diseases in Newborns and Children and the Universal Newborn Screening Panel approved by the Secretary of Health and Human Services. Most recently, the addition of Critical Congenital Heart Defect (CHD), a point-of-care screening, has clouded the lines separating the two newborn screening sections within this Division. Coupled by the Newborn Hearing Screening Programs loss of state funds at the end of the 2010-2011 fiscal year and the need to equalize workload, a decision was made to re-structure the



Division. As an initial step in this process, the Newborn Hearing Screening Section has assumed the role of Point-of-Care screening encompassing both hearing and CHD.

**V. Plans for Upcoming Budget Year:**

**1. Goal: Reduce the number of infants lost to follow-up after initial screening.**

At least four onsite hospital quality improvement visits are planned for the next grant cycle. The EHDI program administrator will work with the PA Chapter of the American Academy of Pediatrics (PA AAP) to identify hospitals in need of an onsite visit. PA AAP will establish an onsite visit team. Each visit team will include the Department's EHDI program administrator, the PA AAP project director who is a consulting physician, and a pediatric audiologist. During the onsite visits, the PA AAP project director and hospital physicians will facilitate a discussion with hospital staff reviewing newborn hearing screening procedures and the facility's hearing screening program. All areas of concern regarding screening equipment, procedures or protocols will be documented during the visit. After the visit, a written report will be completed by PA AAP professional staff and provided to the EHDI program administrator. The report will summarize the visit findings and include specific recommendations on areas in need of corrective action. The EHDI program administrator will then communicate this information to the hospital. Approximately 60 days after each site visit, a follow-up conference call with the onsite visit team members and hospital staff will be conducted and the corrective action items will be reviewed.

**2. Goal: Reduce the number of infants lost to follow-up after second screening.**

PAAP will offer one state-wide teleconference to improve knowledge of the newborn hearing screening process and early childhood hearing loss. The topic and speaker for the teleconference will be selected based on a review of the most current information and research on early hearing detection and intervention. The teleconferences will be promoted through the PA EHDI website, the PA AAP website, the PA AAP monthly newsletter and through broadcast faxes and e-mails to primary care physician practices. PCPs and office staff will earn continuing education credits by completing an evaluation to measure the effectiveness of the teleconference presentation. The teleconference will be recorded and posted on both the PA EHDI website and the PA AAP website for those who are not able to join the live broadcast.

PA AAP will maintain the PA EHDI website. A staff person from PA AAP will serve as the website administrator. At the request of the EHDI program administrator, PA AAP will be able to add new information to the website, modify existing information and remove old information. The EHDI program administrator and PA AAP will also begin to use Google Analytics to measure the number of website users; new users vs. returning users; where users are coming from; what users are viewing; and, how users interact with the website pages.

**3. Goal Enhance the existing out-of-hospital birth hearing screening program.**

PA AAP will be working with the EHDI program administrator to assist in providing refresher training to midwives in the out-of-hospital birth hearing screening network. The EHDI program administrator and PA AAP staff will review referral and screening data from free-standing birthing centers and midwives in the existing network to determine which practices may need refresher training. Each practice will be contacted to schedule the training and a consulting audiologist will provide the onsite training. The training will include information on proper maintenance of screening equipment and a review of proper screening procedures. When possible, a newborn or infant will be present at the training for practice screenings. During the visit, the EHDI program administrator will review program reporting requirements and the procedures for ordering screening supplies.

**4. Improve the services and supports provided by Early Intervention to infants and toddlers who are deaf/hard of hearing and their families.**

EI professional staff will work with the EHDI program administrator to develop two educational workshops that will be offer state-wide. The workshops will be designed to enhance the skills and knowledge of service coordinators, teachers, other related service providers and families in Early Intervention.

Fifteen parent scholarships will be provided to parents with infants and toddlers identified with hearing loss to attend the annual Pennsylvania Low Incidence Institutes that take place in State College, PA.

During this grant cycle information will be shared on a quarterly basis between the EHDI and EI programs. Information that is not personally identifying will be mapped onto the counties of PA to compare numbers of children entering Early Intervention to the numbers of children identified with hearing loss by the newborn hearing screening program.

EI will work with the EHDI program administrator, the Infant Hearing Screening Advisory Committee and key stakeholders to revise and distribute a Parent Satisfaction Survey to all families of infants and toddlers currently enrolled in Part C Early Intervention with hearing loss.

**5. Implement and evaluate the family support program Hands and Voices Guide By Your Side of Pennsylvania.**

During this grant cycle, refresher training will be provided to all PA Guide By Your Side (GBYS) Parent Guides to ensure that their knowledge about information and support related to having a child with a hearing loss remains both current and unbiased. The GBYS Program Coordinator and Parent Guides will perform outreach activities that will focus on hospitals, Early Intervention programs, Local Interagency Coordinating Councils for Part C, audiologists and other relevant agencies. Finally, the EHDI program administrator and the GBYS Program Coordinator will begin a formal evaluation of the new PA GBYS program.