

## **Project Narrative**

### **Introduction**

The Universal Newborn Hearing Screening and Intervention (UNHSI) Program became law in Pennsylvania in July 2002 through the passage of the Infant Hearing Education, Assessment, Reporting and Referral (IHEARR) Act (Act 89 of 2001). Pennsylvania's IHEARR Act empowers the Pennsylvania Department of Health to administer a statewide comprehensive newborn hearing screening and follow-up program. The purpose of the Act is to provide hearing screening for all newborns born in Pennsylvania and to enable infants and their families to obtain a comprehensive and multidisciplinary evaluation, treatment and intervention services at the earliest opportunity. Since the passage of the IHEARR Act, the Pennsylvania newborn hearing screening program has evolved into a unique system of organizations, stakeholders and professionals hosting a seamless system of services for infants screened for hearing loss. Pennsylvania has followed the national trend of screening most infants for hearing loss and then losing a number of them in the follow-up process. This application will discuss our plan to address this issue over the next three years through education, systems enhancement, improved communication, quality improvement and technical assistance.

### **Needs Assessment**

Pennsylvania is a Mid-Atlantic state with a population of 12,742,886 (2011 US Census estimate). The state is comprised of 67 counties, 56 cities, 958 boroughs, 1 incorporated town, and 1,547 townships (2011 Pennsylvania Manual - Volume 120). Forty-eight of Pennsylvania's 67 counties are classified as rural according to the Center for Rural Pennsylvania. Twenty-three percent of the state's population lives in areas that are designated as rural. Rural areas, by definition, must contend with sparse populations and geographic barriers and must also contend with significant health professional shortages. Access to medical care is limited in many rural areas. In 2008, analysis of data from the Pennsylvania Department of Health showed rural Pennsylvania had roughly one physician for every 663 residents, as compared to one for every 382 residents in urban areas of the state. Pennsylvania's population is also diverse in age, race, culture, and linguistic make up. In the southeastern and southwestern corners of the state are the two largest cities, Pittsburgh and Philadelphia. These cities have a large concentration of diverse cultures and languages making communications challenging.

In 2010 there were 142,659 reported occurrent births in Pennsylvania; 138,485 were hospital births and 4,174 were out-of-hospital births. There were 104 birthing hospitals in the state in 2010 with all having a newborn hearing screening program. Almost all Pennsylvania hospitals do aABR screenings. In addition, 23 midwife networks established by the PA newborn hearing screening program across the state were screening newborns for hearing loss. Midwife networks use both aABR and OAE equipment. Reports filed by hospitals and midwives with the newborn hearing screening program indicate that in 2010, approximately 97% of hospital births and 45% of out-of-hospital births completed hearing screening.

Under the provisions of the IHEARR Act both the hospital newborn hearing screening programs and midwife networks submit monthly newborn hearing screening reports to the PA

newborn hearing screening program. The reports contain aggregate information on the number of births; the number of newborns receiving an initial screening; the number of newborns not screened (because of transfer to a hospital, equipment problems or missed screenings); the number not screened because of parent refusal; the number who did not pass the screening before discharge; the number of newborns who were screened after discharge; and, the number who did not pass a final screening. All reports are reviewed by the Newborn Hearing Screening Program Administrator. Any reports that contain obvious data errors are set aside and the Newborn Hearing Screening Program Administrator will contact the hospital or midwife network for clarification. Information for all reports is then entered into an electronic database. Performance data for all hospitals and midwife networks is then tracked over time to measure hospital and midwife screening performance, trends and averages. Quarterly and yearly summary performance reports are produced for all hospitals and midwife networks and then shared with PA Infant Hearing Screening Advisory Committee members, key stakeholders and representatives of the PA Chapter of the American Academy of Pediatrics (PA AAP).

In addition to the monthly newborn hearing screening reports described above, all hospitals and midwife networks are also required to submit referrals to the newborn hearing screening program for any newborn who does not complete a hearing screening and for those who do not pass a final screening. Currently referrals are made on individual forms that are completed by the hospitals and midwife networks. The completed referral forms are then sent to the newborn's primary care physician and to the newborn hearing screening program by fax. The referral forms contain contact information for the parents and a second party; identifying information for the newborn; contact information for the newborn's primary care physician; and, initial and final hearing screening test dates and results. (In 2006 the PA newborn hearing screening program participated in the National Initiative for Children's Healthcare Quality – NICHQ – project. As a result of participating in this project, a space was added to the referral form for information for a second contact. This change significantly helps in the follow-up process and decreases the number of referrals that are lost to follow-up. In 2006, the PA newborn hearing screening program reported a 21% loss to follow-up rate. The 2010 loss to follow-up rate reported was 7%. Although other factors have played a role in reducing the loss to follow-up rate in Pennsylvania, the addition of the space for a second contact on the referral form has been a significant program improvement.)

Referral forms that are received by the newborn hearing screening program are reviewed by one of three follow-up nurses. Information from the referral forms is then manually entered into the Department's newborn hearing screening case management and tracking system. (In December 2011, the Department placed a new OZ eSP system into production.) As part of the follow-up process, the newborn hearing screening case management system will automatically generate specific letters to parents, primary care physicians, audiologists and others at appropriate times, it will build lists of cases for the nurses to work and has text fields to record case notes. The new OZ eSP system also has robust reporting features that allow for accurate and timely monitoring and evaluation of hospital and overall program performance.

In 2011, the PA newborn hearing screening program launched a project with staff from the PA Chapter of the American Academy of Pediatrics to conduct a formal review of hospital newborn hearing screening performance. The purpose of this review was to identify areas where

hospital newborn hearing screening was working well and areas needing possible quality improvement. In this review, data was used from the aggregate hospital monthly reports and from individual referrals from all birthing hospitals for a 16 month period from January of 2010 to April 2011. Specific areas that were evaluated included the overall screening rates; parental refusal rates; initial rates of positive screens; rescreening rates for those newborns failing the initial hospital screening; overall rate of positive screens after the screening and rescreening process; and, the anticipated and actual number of referrals made to the newborn hearing screening program. As a part of the review, delivery hospitals in the state were divided into three groups: hospitals with a large number of deliveries (2,000 or more during the 16 month review period), those with a medium number of deliveries (between 1,000 and 1,999 during the 16 month review period) and those with a small number of deliveries (less than 1,000 during the 16 month review period). Below are some major findings from this review:

1. Overall for the large delivery hospitals 98.6% of all live births received an initial newborn screen. For the most part, these rates were very consistent among the large delivery hospitals with 24 of 28 hospitals having an initial screening rate above 97%. However, a few possible problem areas were identified. For example, Hahnemann Hospital screened only 95% of all births. This represented 106 babies not screened at Hahnemann. Similarly, Hershey Medical Center reported 115 babies unscreened and Abington reported 276 babies unscreened. Because large delivery hospitals do the majority of births, even a small percentage of unscreened babies is significant. In total, 1,125 babies were unscreened in the group of large delivery hospitals.
2. The overall rate of babies not passing their initial screen in the large group of hospitals is 4.3%; however, the rates fluctuate from 1% to 21%. The excessively high 21% initial fail was found only at Crozer-Chester Hospital.
3. In total, at the end of the screening and rescreening process in the large delivery hospitals, 526 babies failed and should have been referred for diagnostic testing. This represents only 0.49% of all babies screened and 0.48% of all babies born. This rate appears to be very low.
4. For the medium delivery hospitals overall parent refusals were only 0.4% of reported births. However, three of the 27 medium delivery hospitals – Ephrata Hospital, Holy Spirit Hospital and Lebanon Hospital accounted for 72% of all parent refusals in this group.
5. For the medium delivery hospitals 91% of the newborns who did not pass the initial newborn hearing screening were rescreened. However standing out in this group was Sewickley Hospital where 61 newborns failed the initial screening but only 6 were reported as being rescreened.

In 2010 in the annual CDC EHDI survey, Pennsylvania reported that 136,908 newborns (or 96% of total reported births) completed hearing screening and 1,931 infants did not pass a final screening. Of those infants that did not pass, 1,164 were later diagnosed with normal hearing, 176 were diagnosed with a permanent hearing loss, 193 were diagnosed with a non-

permanent conductive hearing loss, 6 expired, 220 parents declined services, 34 moved out of state and 138 were lost to follow-up (7%). Of those 138 that were lost to follow-up, 99 were lost to follow-up after the initial screening, 34 were lost after the final screening and 5 were lost after receiving an inconclusive diagnostic audiological evaluation.

Since 2008 the state newborn hearing screening program and the PA Early Intervention (EI) Program have conducted an annual survey of all parents who have children enrolled in EI programs with hearing loss. Each year newborn hearing screening program staff, Infant Hearing Screening Advisory Committee members, key stakeholders and EI staff develop the survey document. The survey is mailed by the Early Intervention program and completed surveys are collected and analyzed by EI staff. The survey results are shared with a number of organizations including the Infant Hearing Screening Advisory Committee; ERCHL (Education and Resources for Children with Hearing Loss); OCDEL (Office of Child Development and Early Learning); and, the state Interagency Coordinating Council.

In the 2011 Parent Survey, 78% of parents responded that their child was first seen by a pediatric audiologist before they were 3 months of age and an additional 12% responded that their child was seen before they were 6 months of age. Sixty-six percent of parents responded that their child was diagnosed with hearing loss within 30 days from the date of final screening and an additional 13% responded that they received a diagnosis within 60 days from the date of the final screening. Ninety-two percent of parents responded that, “the information I received from the medical professionals (pediatrician, audiologist, ENT-- Ear/Nose & Throat specialist, etc.) about my child's hearing loss was similar/consistent”.

In the 2011 Parent Survey, 99% of parents responded that, “In Early Intervention, my child was assessed in all developmental areas (for example, physical and motor skills, social and emotional, communication, adaptive development/self help and cognitive skills) to determine his/her progress. In a question about communication options, 95% of parents responded that they received information on Auditory-Verbal; 93% on Auditory-Oral; 86% on ASL; 70% on Cued Speech; and 82% reported that they received information on Total Communication.

In the 2011 Parent Survey, 94% of parents responded that they were satisfied with their EI program and 91% responded that their child's EI services made them better prepared to meet their child's needs.

From reviewing the results of the 2011 Parent EI survey the following areas were identified as needing improvement: More work needs to be done to give opportunities to parents with children recently diagnosed with hearing loss to have contacts with other parents who have experience with their own deaf or hard of hearing children; more work needs to be done to give parents with children recently diagnosed with hearing loss to have contact with adults who are deaf or hard of hearing; and, parents need to have access to more information about national, state and local organizations related to deafness and hearing loss.

## Methodology

In December 2011 the PA newborn hearing screening program placed the OZ eSP system into production. This web-based product provides a comprehensive case management system for the newborn hearing screening program and will aid the program in both monitoring and evaluation activities. Currently, three Department newborn hearing screening nurses use the system for case management and follow-up activities. Under current processing procedures, blood-spot filter papers are sent by hospitals and midwives to one of two testing laboratories. While performing the blood-spot test, the laboratories create an electronic record for each newborn. The laboratories then send the electronic records for all newborns to the Department daily and selected demographic information from each record is automatically imported into the OZ eSP system to create a unique record for each newborn.

As the follow-up nurses receive individual faxed referrals from hospitals and midwives for newborn who did not complete a hearing screening and, for those that did not pass a final screening, they will search the OZ eSP system for the newborn's record and add hearing screening results and other information to the electronic record from the referral form. The search capability of the OZ eSP system allows for very broad searches in identifying referred cases. The ability to add additional contacts to each case such as father, foster parents, grandparents, and professional providers is also available. The system itself is designed so that a nurse working a case can see, via a one page glance, where the case stands in the follow-up process. Case letters are automatically generated within the system, according to the client care path, and can be sent to the newborn's contacts (parents, primary care providers, hospitals, early intervention providers) and are printed on demand in the nurse's work area. A "faxback" form has also been created. This form is also available within the system for immediate printing, allowing for more efficient follow-up to the newborn's primary care provider. Primary care provider information is easily editable to reflect changes, such as a provider who has moved to another location or for a change in telephone and/or fax number. Providers contained within the system can also be searched for by individual or practice name. A "Hearing Journey" feature within the system automatically places cases into identifiable lists for easier follow-up activities. The system has the ability to track appointments with an otolaryngologist, an audiologist or for Early Intervention linkage. The system creates a unique identification number for each case to allow for confidential access and data sharing of records.

To achieve the full benefits of the OZ eSP system it will be necessary to develop and implement a plan for full electronic reporting by hospitals and midwives. To begin this process the Department has begun discussion with staff from OZ Systems, Geisinger Medical Center and Birth Care & Family Health Services. Geisinger Medical Center is a physician-led health care system spanning 43 counties and serving 2.6 million people in central and northeast Pennsylvania. Geisinger participated with the PA newborn hearing screening program in the 2006 NICHQ project, is an active member of the Hospital Work Group and is known nationwide for its efforts in the development of electronic medical records. Geisinger also uses the OZ eSP system in its newborn hearing screening program. Birth Care & Family Health Services is a free standing birthing center located in Central Pennsylvania. It serves mainly the Amish and Mennonite communities and delivers approximately 450 out-of-hospital birth babies per year. Birth Care staff works closely with the newborn hearing screening program and the facility has

recently received new hearing screening equipment from the Department with appropriate software that will allow for electronic reporting of hearing screening results. Both Geisinger Medical Center and Birth Care have agreed to participate with the newborn hearing screening program in a pilot effort to begin electronic reporting to the new OZ eSP system. OZ staff is assisting the Department with developing and implementing this pilot program which should start in the summer of 2012. Results from the pilot will be used to develop a plan to move forward with electronic reporting from other hospitals and midwife centers.

Onsite technical assistance visits have been made to hospitals identified as needing improvement in loss to follow-up rates. PA AAP staff coordinated the onsite technical assistance visits with a team that included a neonatologist, pediatric audiologist and the newborn hearing screening program administrator. The team reviewed the hospital's newborn hearing screening program with hospital staff, including the newborn hearing screening coordinator, screeners and maternity nurse managers, to improve performance across 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
- 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

A report summarizing the visit, including identifying strengths and weaknesses, and recommendations for improving the newborn hearing screening program, was provided to hospital staff.

Under this grant these onsite technical assistance visits will continue but will also include a quality improvement program. The onsite visit team will assist the hospital staff in identifying an area in need of change and implementing a PDSA cycle. Information on successful quality improvement programs will be shared with other hospitals.

In order to develop and share information on hospital-based newborn hearing screening program best practices, a quarterly teleconference is held with the Hospital Workgroup established by the Department. This workgroup consists of hospital newborn hearing screening coordinators and maternity nurses who are interested in improving their hospital's newborn hearing screening program. Recently, a representative from the Hospital & Healthsystem Association of Pennsylvania (HAP) joined the work group. The Hospital & Healthsystem Association of Pennsylvania is a statewide membership services organization that advocates for nearly 250 Pennsylvania acute and specialty care, primary care, long-term care, home health, and hospice providers, as well as the patients and communities they serve. Hospital Workgroup topics have included maximizing appropriate follow-up for infants following discharge and reviewing the reasons for high fail rates for initial screens and high rates of referral to the Department. Best practice information is obtained and shared during these teleconferences through discussion by participants.

Hospital Workgroup teleconferences will continue to be held quarterly and best practice information will be distributed to hospitals that are not currently members of the workgroup.

On-Line Early Hearing Detection and Intervention (On-Line EHDI) is a web-based continuing medical education (CME) resource for physicians. On-Line EHDI offers a selection of 6 case study learning modules that qualify for .5 CME credits each through the University of Pittsburgh School of Medicine, Center for Continuing Education in the Health Sciences.

The PA AAP will continue to maintain On-Line EHDI and promote it through the PA AAP website and PA AAP newsletter. Department letters to physicians will also include information about On-Line EHDI.

An educational teleconference for PCPs will be offered each year to improve knowledge of the newborn hearing screening process and early childhood hearing loss. This teleconference will be one of the PA AAP's "Let's Talk" teleconference series, a proven and successful format for providing continuing education credits to pediatricians through the University of Pittsburgh School of Medicine, Center for Continuing Education in the Health Sciences. The "Let's Talk" teleconferences have been offered for 12 years and are a popular and effective way to communicate current health care information to physicians and their staff.

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. Rachel St. John, MD was our most recent teleconference speaker and she presented "Beyond Newborn Hearing Screening: Case Studies with Deaf and Hard of Hearing Patients". Other speakers include Karen Fowler and Arti Pandya, MD, discussing "Late Onset and Progressive Hearing Loss" and the effect of CMV.

Let's Talk teleconferences are promoted through the PA EHDI website, the PA AAP website and the PA AAP monthly newsletter as well as through broadcast faxes and e-mails to PCP practices. PCPs and office staff earn continuing education credits by completing an evaluation to measure the effectiveness of the teleconference presentation. The teleconference will be posted on the PA EHDI website and the PA AAP website for those who are not able to join the live broadcast.

Recognizing the importance that state newborn hearing screening programs play in ensuring the availability of accurate and user-friendly information pertaining to newborn hearing screening, diagnosis, and early intervention services the PA newborn hearing screening program launched an effort to develop a PA Early Hearing Detection and Intervention (EHDI) website. In June 2010, PA newborn hearing screening program staff along with staff from PA AAP launched the PA EHDI website ([www.paearlyhearing.org](http://www.paearlyhearing.org)). This site was several years in the making. Staff from both the PA newborn hearing screening program and PA AAP worked closely with members of the Infant Hearing Screening Advisory Committee and key program stakeholders on website layout and content. To make navigation easy, the website contains individual pages for key stakeholders including families, physicians, audiologist, birth facilities and Early Intervention staff. The family page and the physician page feature a link to find an audiologist. Selecting on this link will take a user to a map of Pennsylvania. Once on the PA map page a user

then selects a part of the state they are interested in and that will produce a list of counties in the selected region. The user then can select a county and that will produce a list of all “pediatric” audiologists in that county along with their contact information including address, telephone number and email address (when provided). Recently, information for the new PA Guide By Your Side (GBYS) Program was added to the PA EHDI website. This page includes a referral form for PA GBYS services that parents can complete online.

To advertise the website, a rack card was designed and distributed; information on the site was distributed at a state-wide meeting of the PA Academy of Audiology; the website was announced at state-wide meetings of Early Intervention service providers; email notifications were sent to all hospitals with newborn hearing screening programs; information advertising the site was added to all newborn hearing screening program correspondence; and, a reference to the website was added to the signature address for all staff in the newborn hearing screening program. In the fall of 2012 social media, including Facebook, will also be used to promote the website. At the February 2011 Early Hearing Detection and Intervention (EHDI) Conference in Georgia, Pennsylvania was proud to receive the first EHDI website of the year award!

During the past year Ms. Lynn Hepp, the EPIC-EHDI (Educating Physicians in their Community – Early Hearing Detection and Intervention) Program Director at the PA AAP, and Mr. Arthur A. Florio, the Program Administrator for the PA Newborn Hearing Screening Program, participated with staff from the National Centers for Hearing Assessment and Management (NCHAM) and others to develop an EHDI Web Resource Guide. This guide has been published and is available on the NCHAM website. Additionally, during the past 4 months, Mr. Florio also served on a national committee created by NCHAM to evaluate and select the recipient of the 2012 EHDI Website of the Year Award. This award will be made in March 2012 at the national EHDI conference in St. Louis.

Over the next year efforts will be undertaken to enhance the PA EHDI website. Plans are underway to add a user online survey. This brief 5-question survey will be presented to one of every 25 or so users and will be voluntary. Responses to the survey will allow program staff to identify who is visiting the site (parents, audiologists, primary care physicians Early Intervention staff or others); how a user learned about the website; what the user liked or didn’t like about the site; if the user found the information they were looking for and was the information helpful; and, does the user have recommendations to make the website better. Modifications are also being made to the website design to further improve the ease of use.

To foster a strong link between the hearing screening process and the diagnostic process, the PA AAP will review how referrals are made to audiologists as a way to improve loss to follow-up after failed hearing screenings. Currently, the method of referral of babies for diagnostic testing after a failed newborn screen varies from hospital to hospital. Some hospitals have worked with their medical staffs to develop direct referral linkages with audiology centers in their communities or hospital systems. In other cases, however, the decision of referral for diagnostic testing is left solely to the PCP and that referral may be made to any of a number of audiology services in that particular community. There is no information currently available on practice patterns as they relate to diagnostic testing. Additionally, PCPs do not always know the capabilities of audiology centers in their communities to make the best decision on referrals.

During this grant cycle, the PA AAP will develop a mechanism to track current referral patterns by PCPs and create an appropriate survey tool to access the capabilities of audiology centers. Information obtained from this process will be shared with hospitals and PCPs to develop and strengthen relationships with audiology centers in their communities and improve referral rates. The capabilities of audiology centers will be added to the “Find an Audiologist” feature of the PA EHDI website so that families and PCPs have convenient access to this information.

Another potential strategy for evaluating the quality of the overall screening and diagnostic process for an EHDI program is to review cases of children who are diagnosed later to evaluate if they potentially could have received an earlier diagnosis. Clearly some of these children may present later in childhood because of either progressive hearing loss or mild hearing loss that was not detected earlier. However, in Pennsylvania there has never been a review of these cases to determine any potential quality issues. During this grant cycle, the PA AAP will perform such a review as a pilot. Because many of the cases of hearing loss are diagnosed in a relatively small number of centers, we propose to work with the two largest audiology centers in the state to determine the number of children diagnosed with hearing loss later in childhood. The PA AAP will then review the screening process for these children to determine if there are any possible issues that could have led to an earlier diagnosis. Possible examples of such issues may include:

1. Cases with high risk indicators that were not followed appropriately
2. Cases with an initial failed screen that did not receive a diagnostic evaluation
3. Cases with an initial failed screen that was not diagnosed in infancy despite a full diagnostic evaluation
4. Cases of babies who passed the newborn screen but during the screening process failed an OAE but passed the aABR

The expected outcome of such a review will be to determine the area upon which to focus in improving the overall diagnostic rate of the Pennsylvania’s EHDI program. This rate currently in PA is approximately 1.4/1000 births but the program has a goal of increasing this rate. While this review will not allow us to determine cases that are missed because of problems in screening quality, it will give us information regarding the follow-up evaluations of babies failing the screening process or those passing the screen but who still had high risk factors for hearing loss.

The IHEARR Act (Act 89 of 2001) empowers the Department of Health to administer a statewide comprehensive newborn hearing screening and follow-up program. This Act specifically mentions that out-of-hospital births will be screened for hearing loss within 30 days of birth. In 2003, the newborn hearing screening program performed an analysis of the distribution and concentration of out-of-hospital births around the state using statistical data provided by the Department’s Bureau of Health Statistics and Research. This analysis enabled program staff to determine the locations where portable hearing screening units would be most beneficial. (Every two years the newborn hearing screening program obtains updated data from the Bureau of Health Statistics and Research to update the original analysis.)

Portable hearing screening equipment was purchased and provided to free-standing birthing centers and midwives in areas with high concentrations of out-of-hospital births. Representatives from the manufacturer or distributors of the portable hearing screening equipment and newborn hearing screening staff provide hands-on training to screeners. Screeners agree to submit screening data to the newborn hearing screening program and to refer infants not passing screenings to the Department for follow-up. Today 23 midwife networks are in place around the state. The table below depicts the number of out-of-hospital births screened for hearing loss between 2005 and 2010.

**Out-of-Hospital Births Screened for Hearing Loss**

Calendar Year	Total Out-of-Hospital Births	Newborns Screened	Percent Screened
2010	4,174	1,884	45%
2009	3,944	1,632	41%
2008	3,900	1,595	41%
2007	3,805	1,227	32%
2006	3,759	1,189	32%
2005	3,606	947	26%

Activities that will be undertaken in the out-of-hospital birth program during this grant period will include:

1. Newborn Hearing Screening Program staff will conduct onsite visits to 10 midwife networks each year. During these visits information will be collected on the population served; where births occur (in the midwife center, home or hospital – some midwives have “privileges” at local hospitals); when and where newborn hearing screenings are done; and what hospitals the midwives have relationships with. During the visits newborn hearing screening program staff will review how to properly complete and submit monthly reports and referral forms. Staff will also verify that each midwife network has information on local audiologists when referrals are required.
2. During the fall and winter of 2011, eight new Otodynamics Otocheck OAE hearing screening units were placed at midwife networks. These units replaced old aABR equipment. Beginning in May 2012 all midwife networks that received the new equipment will receive “refresher” training. The instructor for the refresher training will be Dr. Sherman Lord, a pediatric audiologist who is familiar with the new equipment and with newborn hearing screening. During the training Dr. Lord will cover how to care for and maintain the equipment; and, will do hands on refresher training in the use of the equipment. Several midwife networks will attend each training session so that screeners from different networks can share information on screening protocols and techniques. These refresher trainings will be repeated yearly.

To improve the services and supports provided by Early Intervention to infants and toddlers who are deaf/hard of hearing and their families, professional development efforts will be concentrated in three focus areas:

- a) provide a minimum of two educational workshop series across the state per year designed to enhance the skills and knowledge of service coordinators, teachers, other related service providers and families in Early Intervention;
  - b) provide parent scholarships to support parents' attendance at workshops and statewide training institutes, and,
  - c) enhance and expand online courses to support participants seeking independent self-paced learning and to meet the professional development needs of a large state.
- (A) Educational workshops: The topics selected for these two statewide workshop series will be based on the feedback from parents and professionals in previous workshops obtained through standardized evaluation forms, an analysis of the annual parent survey and suggestions from the Infant Hearing Screening Advisory Committee. At least one workshop each year will be face-to-face provided in the three state leased training centers located in west, central and eastern regions of Pennsylvania. Personnel in Early Intervention Technical Assistance (EITA), which is the state Part C training and technical assistance provider, will develop, coordinate, implement and evaluate the trainings. EITA is uniquely qualified to provide educational workshops on topics on Early Intervention for infants and toddlers with deafness and hearing loss and their families because of their contractual relationship to the state Part C agency. In the last 5 years, over 2,300 people have participated in EITA workshops specifically targeting these infants/toddlers and their families; this represents 47 sessions of in-service education. Attendees have included parents who have children with hearing loss, teachers of the deaf and hard of hearing, speech and language clinicians, audiologists, educational sign language interpreters, consultants, service coordinators, and administrators working with children with deafness and hearing loss.

The second workshop each year may be completed in a similar face-to-face methodology or may be presented in a videoconference format based on the nature of the content being presented. EITA has the capacity to broadcast a video conference at low cost from one of the three state leased training centers to several sites around the state. This format allows Early Intervention staff to access the workshop content while minimizing the need for extensive travel and costly hotels. EITA has been using this format to advantage for many years.

- (B) Parent scholarships: To encourage parents with infants and toddlers to attend educational workshops, the Department of Health through EITA has supported parent scholarships at 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 5 years, about 15 parent scholarships each year have been distributed to all the families who applied. All requests received were honored.

- (C) Remote access/online independent study: A third professional development opportunity for service coordinators, Early Intervention service providers and families is the online course developed and implemented in the past year of this grant. The current online course is a self-paced online course developed by EITA featuring Mary Koch-Cline. "Orientation to Deafness and Hearing Loss in Infants and Young Children" was made available statewide in 2010. This course consists of nine modules including: Introduction; Benefits of Early Intervention; Communication and Language; Modalities and Controversies; Understanding Hearing; Hearing Technology; Early Intervention; Web Resources; and, Review. The course includes learning objectives and activities, videotaped materials, downloadable slides and tape transcripts as well as quizzes for each segment. To date, 28 people have completed the course and 12 more are currently registered. Feedback has been positive. In 2012-13 further evaluation of this course will be conducted with refinements made, as needed. Outreach will be conducted to increase enrollment in the course. In subsequent years of this grant these resources will be expanded and enhanced in order to make additional self-paced and individualized learning experiences available to personnel and families in Early Intervention.

This grant opportunity will be used to provide a range of resources and materials to improve Early Intervention services and supports including:

- (A) Through the EITA Short Term Loan Kit program supported by this grant, EITA has been able to provide curricula and materials on a loan basis to those who are working with infants and toddlers with deafness/hearing loss and their families. During the current year, these materials will be reviewed and updated; in subsequent years of this grant EITA will continue to add to these materials 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 will be utilized from users to determine modifications to the loan system.
- (B) A limited bank of FM systems suitable for infants and toddlers with hearing aids will be acquired as part of the current grant activities. The development of a customized FM Loaner Bank will be piloted and evaluated in 2012-13 and subsequent years of the grant. The FM Loaner Bank will be operated in collaboration with pediatric audiologists associated with the PA EHDI program.
- (C) The EITA publication "Getting Started" which is a family guide to communication choices is currently required by the state Part C agency to be distributed in Early Intervention to families of infants, toddlers and young children with deafness/hearing loss. The publication was originally written by parents for parents and is being updated, based on feedback and input from families in 2012-13 (including the original group of parent-authors), professionals, the Infant Hearing Screening Advisory Committee and interested others. The process of printing and keeping this publication current will continue in subsequent grant years.

As part of this grant on an annual basis, EITA distributes a Parent Satisfaction Survey to all families of infants and toddlers currently enrolled in Part C Early Intervention. The original

purpose of this survey was to assess whether parents were linked in a timely way with appropriate EI services and to determine if parents were informed about the full range of communication options. In the past years of this grant the survey has evolved and it is now divided into three parts: Experiences Before Early Intervention; Experiences in Early Intervention; and, Perceptions of the Quality of Early Intervention Services and Levels of Satisfaction with Early Intervention. Of these, the first section specifically provides valuable feedback not just to EI, but to the Infant Hearing Screening Advisory Committee, the medical community, including pediatricians, audiologists and other medical professionals serving this population. A data analysis shows that in 2011 a total of 337 surveys were mailed with returns of 105 completed surveys, for a response rate of 31%.

A snapshot of the data indicates that with respect to EHDI's "1-3-6" recommendation:

- 96% of the respondents reported that "My child was first screened for a hearing loss at birth or before s/he was 1 month old".
- 78% of the respondents reported that, "My child was first seen by a pediatric audiologist for a comprehensive hearing test (not a screening test) before s/he was three months old."
- 70% of the respondents reported that, "My child entered EI by the time s/he was six months old."

In addition, families were asked how long it took to get from the first hearing screening to the point of diagnosis.

- 66% reported they were able to get the child's diagnosis within 30 days of the first screen.
- Another 13% reported diagnoses within 60 days.

Helpful feedback is also provided concerning the quality and effectiveness of services in Early Intervention as well as parent satisfaction. For example:

- 96% of the respondents reported that, "In early intervention I was given access to at least one staff person who is qualified in the areas of deafness or hearing loss."
- 90% reported that "Overall, my child's EI services made me feel better equipped to care for his/her needs".

Revisions to the annual survey have been balanced against the need to keep the survey brief while still providing more informational feedback to Early Intervention as well as the EHDI Advisory Committee.

Parent survey results are annually shared with Department of Health Newborn Hearing Screening Advisory Committee, the Early Intervention State Interagency Coordinating Council (SICC) and other groups (e.g., ERCHL, Educational Resources for Children with Hearing Loss, the school-age Advisory group to the PA Department of Education).

Over the past years of the grant collaboration strategies were developed to share and compare data between Early Intervention and Newborn Hearing Screening which will continue

in subsequent grant years. On a quarterly basis, data from the Early Intervention data system will be compared to data from the Newborn Hearing Screening program. For this purpose, 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 in Newborn Hearing screening.

On an annual basis, data on numbers of children in yearly cohorts (starting with dates of birth in 2009) will be compared between Early Intervention and Newborn Hearing Screening, also using statewide mapping, as needed.

Efforts will also continue to encourage local Infant/Toddler Early Intervention programs to gain parental consent to directly release identifiable information about children with hearing loss to the Department of Health. To date, the state Part C agency has issued two relevant Policy Announcements: EI-2009 #01, Recommendations for Children who are Deaf and Hard of Hearing, and EI-2010 #02 Release of Information. Current work is focused on the development of Communication Plans to supplement the IFSP/IEPs of infants and young children with hearing loss. Training was conducted by the state Part C agency and EITA on the implementation of these policies. In subsequent years of this grant both policies will be reviewed and updated/reissued as needed.

Hands and Voices Guide By Your Side of PA (GBYS) was started in the fall of 2011 utilizing the current grant funding. GBYS is dedicated to directly supporting families and their infants and toddlers who are newly diagnosed with hearing loss by offering them the opportunity to talk to or meet face-to-face with a Parent Guide. Parent Guides are parents of children who are deaf, hard of hearing and deafblind who have received specialized training. Parent Guides are able to bring their direct experience, specialized knowledge, and personal compassion to the role while making the family needs their primary focus.

The activities to meet this objective focus on scaling up the Guide By Your Side program to support all the interested families in Pennsylvania who meet the program's eligibility criteria. Baseline data will be collected from January 2012 through December 2012 to determine the number of referrals received and the number of families who received services through the program. In 2013, annual target numbers of families to be served will be established. Annual training will be provided to all Parent Guides to ensure that their knowledge about information and support related to having a child with a hearing loss remains current and unbiased. New Parent Guides hired will receive comprehensive orientation and training.

- (A) To achieve saturation across Pennsylvania, outreach events will be held or attended by the GBYS Program Coordinator and Parent Guides. These events may be single events or in combination with larger conferences. GBYS will partner with the state's Part C training system, EITA, as well as the PA Department of Health to more effectively conduct the public awareness campaign and outreach events. Outreach will focus on hospitals, Early Intervention programs, Local Interagency Coordinating Councils for Part C, audiologists and other relevant agencies.

- (B) In 2012 Tuscarora Intermediate Unit #11, the fiscal agent for GBYS and the Department of Health initiated a “Business Partner Agreement” that allows 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 and reported to the Department of Health. This “direct referral” will greatly increase the number of families participating in the program. It will also raise awareness of the support that Pennsylvania’s EHDI program is providing to families through GBYS.
- (C) As part of the services provided to families with infants/toddlers with hearing loss the Parent Guides will provide two resources. The “Guided Family Notebook” was developed based on national Hands & Voices models and contains information on audiograms, communications choices and decision-making, American Sign Language, Auditory/Oral Education, Auditory-Verbal Therapy, Cued Speech, Signing Exact English, Total Communication, Hearing Aids, Cochlear Implants, and Early Intervention. The second resource is a Care Coordination Plan Binder. The Binder contains the Early Hearing Detection and Intervention Care Coordination Plan, which was developed in Pennsylvania to provide a useful tool for families and the professionals who help them to handle the information, decision-making, and activities involved with caring for children diagnosed with hearing loss. Both of these resources have received very positive responses from the parents to whom they were given. In 2013 and subsequent years of this grant, a survey will be designed to solicit family input on the usefulness of these two resources.
- (D) In 2012 program evaluation will begin and will expand in subsequent years. Program evaluation will include an analysis of data such as:
- Number of families served
  - Type of service provided (face to face, phone, videoconference or using other technology)
  - Parent satisfaction
  - Utilization of staff
  - Estimated costs of providing support
  - Effectiveness of database
  - Other information, as determined by the Department of Health

As referenced previously the “Business Partner Agreement” between TIU #11 and the PA Department of Health allowed GBYS to receive the names of families with newly diagnosed infants and young children. In 2012-13 fiscal year, these “direct referrals” will be increased to include infants who participated in the Newborn Hearing Screening program and received a screening that indicated a need for follow-up but who did not return for the follow up appointment. GBYS will begin in 2012 and continue in subsequent years to provide a personal phone call from a Parent Guide or the Program Coordinator to each family to encourage them to return for the critical follow up appointment (whether that is pediatric, audiological or other needed appointment). The Parent Guide or Program Coordinator will explain the rationale for the follow up appointment and answer any relevant questions. In 2013 and subsequent years , Pennsylvania Department of Health  
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GBYS and the Department of Health will analyze the data to determine the impact of the GBYS phone calls on reducing the loss to follow up.

Another strategy to reduce loss to follow up will be to prepare and disseminate public awareness cards describing the GBYS program available at the Newborn Hearing Screening sites. In 2012 and 2013, data will be analyzed to see if parents are motivated to return to their follow up appointment if they realize that they may be eligible for services from GBYS.

The successful progress of the PA newborn hearing screening program is made possible through significant collaboration and input from the Infant Hearing Screening Advisory Committee. This committee was established in 2001 with the passage of the IHEARR Act (Act 89 of 2001). By statute the committee has six-members who are appointed by the Secretary of Health. All members serve a term of three (3) years and may be re-appointed once. The committee operates under a set of Bylaws and meets four times per year. All meetings are advertised and opened to the public. At least one member of the Committee must be either a Family Physician; an Otolaryngologist; a Neonatologist; a pediatrician; or, a member of a medical profession that has an interest in newborn hearing screening. One member must be an audiologist with training and experience in pediatric care. And one member must be the parent of a child with deafness or hearing loss.

By statute the purpose of the committee is to advise and make recommendations to the Department of Health regarding infant hearing education, assessment, reporting and referral, on issues including but not limited to, program regulation and administration, diagnostic testing, technical support and follow-up. They are also to provide assistance to the Department with its responsibility to implement and administer the statewide Infant Hearing Education, Assessment, Reporting and Referral (“IHEARR”) Act (11 P.S. § 876-1, et. seq.).

Recently the committee has provided guidance and assistance to the Department in the creation and implementation of the new Pennsylvania Guide By Your Side Program; in the development of the PA Early Hearing Detection and Intervention (EHDI) Website ([www.paearlyhearing.org](http://www.paearlyhearing.org)); and have provided technical assistance in the development of the PA EHDI Care Coordination Plan. The two audiologists currently on the committee have also participated as team members in onsite Quality Assurance visits to several hospital newborn hearing screening programs. In 2012, the committee plans to assist the Department in updating the existing newborn hearing screening program guidelines; will continue to oversee and participate in onsite Quality Assurance visits to hospital newborn hearing screening programs and, will assist the Department in a review to improve audiology reporting of diagnostic results to the newborn hearing screening program.

## Work Plan

<b>1 Goal: Reduce the number of infants lost to follow-up after initial screening</b>				
1.1 Objective: Provide technical assistance and quality improvement programs to hospitals that demonstrate high lost to follow-up rates				
Activity	Responsible party	Start	End date	Evaluative measure
a) Identify birth hospitals with high loss to follow-up rates by reviewing hospital monthly reports	<ul style="list-style-type: none"> <li>PA AAP managing physician</li> <li>DOH program administrator</li> <li>PA AAP project manager</li> </ul>	Current	On-going (quarterly)	Lost to follow-up rates for specific hospitals decrease and data quality on referral forms improves.
b) Review hospital monthly reports and compare failed screen numbers to referral numbers, refer for technical assistance when discrepancy indicated	<ul style="list-style-type: none"> <li>DOH program administrator</li> <li>PA AAP project manager</li> <li>DOH nurse consultants</li> </ul>	Current	On-going (monthly)	The number of failed screens and referrals reported to DOH on a monthly basis are consistent
c) Implement quality improvement program in hospital newborn hearing screening programs	<ul style="list-style-type: none"> <li>DOH program administrator</li> <li>PA AAP project manager</li> <li>PA AAP managing physician</li> </ul>	Fall 2012	Ongoing	Lost to follow-up rates for specific hospitals decrease and data quality on referral forms improves.
d) Document and distribute best practice suggestions from hospital quality improvement programs	<ul style="list-style-type: none"> <li>DOH program administrator</li> <li>PA AAP project manager</li> <li>PA AAP managing physician</li> </ul>	Fall 2012	Ongoing	Lost to follow-up rates and data quality on referral forms improves.
1.2 Develop and share best practices with hospital workgroup and provide opportunity for input on policy issues				
Activity	Responsible party	Start	End date	Evaluative measure
a) Maintain hospital workgroup through regular email	<ul style="list-style-type: none"> <li>DOH program administrator</li> </ul>	Current	Ongoing	Regularly scheduled calls and informal feedback on the discussions during

communications and quarterly conference calls				the calls.
b) Document and distribute best practice suggestions from hospital workgroup	<ul style="list-style-type: none"> <li>• DOH program administrator</li> <li>• PA AAP project manager</li> <li>• PA AAP managing physician</li> </ul>	Current	Ongoing	Lost to follow-up rates and data quality on referral forms improves.
<b>2 Goal: Reduce the number of infants lost to follow-up after second screening</b>				
2.1 Objective: Improve communications with PCP office				
Activity	Responsible party	Start	End date	Evaluative measure
a) Provide educational information about Online-EHDI web-based training to PCPs through PA AAP newsletters and copies of patient letters	<ul style="list-style-type: none"> <li>• DOH Nurse consultants</li> <li>• PA AAP project manager</li> <li>• DOH clerical support</li> </ul>	Current	On-going	Increase number of PCP offices that respond to requests for information from DOH Nurse Consultants
2.2 Objective: Provide educational opportunities to PCPs on the hearing screening process and early childhood hearing loss				
Activity	Responsible party	Start	End date	Evaluative measure
a) Host an annual teleconference on hearing screening issues and early childhood hearing loss	<ul style="list-style-type: none"> <li>• PA AAP managing Physician</li> <li>• PA AAP project manager</li> </ul>	Current	On-going	Post teleconference feedback shows an increased knowledge of hearing screening process
b) Provide web-based training and free CMEs on hearing screening case studies and diagnostic protocols	<ul style="list-style-type: none"> <li>• PA AAP project manager</li> <li>• PA AAP managing physician</li> </ul>	Current	On-going	Review questions show an increased knowledge of hearing screening process
2.3 Objective: Improve education, communications and coordination between families, PCPs, audiologists, Hospitals and DOH to ensure continuity of care				
Activity	Responsible party	Start	End date	Evaluative measure
a) Market the PA EHDI Website to user groups	<ul style="list-style-type: none"> <li>• DOH Program Administrator</li> <li>• PA AAP Project</li> </ul>	Fall 2012	Ongoing	Increase the number of PA EHDI website users

	Manager			
<b>2.4 Objective: Improve PCP referrals to audiologists</b>				
<b>Activity</b>	<b>Responsible party</b>	<b>Start</b>	<b>End date</b>	<b>Evaluative measure</b>
a) Track current patterns of referral to audiologists by PCPs	<ul style="list-style-type: none"> <li>• DOH Program Administrator</li> <li>• PA AAP managing physician</li> <li>• PA AAP Project Manager</li> <li>• Advisory Committee</li> </ul>	Fall 2012	Spring 2015	Improve the referral rates to audiologists and the timeliness of these referrals
b) Assess ability of diagnostic centers and audiology practices	<ul style="list-style-type: none"> <li>• DOH Program Administrator</li> <li>• PA AAP managing physician</li> <li>• PA AAP Project Manager</li> <li>• Advisory Committee</li> </ul>	Fall 2012	Spring 2014	Improve the ability of PCPs to make an appropriate and timely referral for a diagnostic evaluation
c) Determine referral quality issues of children diagnosed with late onset hearing loss or mild hearing loss later in childhood	<ul style="list-style-type: none"> <li>• DOH Program Administrator</li> <li>• PA AAP project manager</li> <li>• PA AAP managing physician</li> </ul>	Fall 2012	Spring 2015	Increase the overall diagnostic rate in Pennsylvania
<b>3 Goal Enhance the existing out-of-hospital birth hearing screening program</b>				
3.1 Objective: Provide assistance and support to the existing out-of-hospital birth hearing screening network.				
<b>Activity</b>	<b>Responsible party</b>	<b>Start</b>	<b>End date</b>	<b>Evaluative measure</b>
a) Onsite visits to 10 midwife networks each year	<ul style="list-style-type: none"> <li>• DOH Program Administrator</li> </ul>	Current	On-going	Accurate monthly reports, complete and timely referrals
3.2 Objective: Conduct yearly midwife “refresher” training				
<b>Activity</b>	<b>Responsible party</b>	<b>Start</b>	<b>End date</b>	<b>Evaluative measure</b>
a) Yearly equipment refresher training	<ul style="list-style-type: none"> <li>• DOH Program Administrator</li> </ul>	Summer 2012	On-going	Positive training evaluations
<b>4 Goal: Improve the services and supports provided by Early Intervention to infants and toddlers who are deaf/hard of hearing and their families.</b>				
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.				
Activity	Responsible party	Start	End date	Evaluative measure
a) Provide educational workshops to enhance the skills of service coordinators and other Early Intervention providers serving children with hearing loss and their families.	• EITA project manager	Current, annually	On-going	Positive training evaluations
b) Provide parent scholarships to statewide annual Low Incidence Institutes	• EITA project manager	Current, annually	On-going	Positive feedback from participating parents through surveys
c) Create web-based training courses based on the educational workshops and other relevant topics.	• EITA project manager	Current	On-going	Enrollment/course completion data and post test scores to demonstrate improved understanding of the needs of children with hearing loss and their families

4.2 Objective: Provide a range of resources and materials to improve Early Intervention services and supports

Activity	Responsible party	Start	End date	Evaluative measure
a) Provide educational resources through Short Term Loan Kits	• EITA project manager	Current	On-going	# of kits utilized by programs Solicit feedback on usefulness of kits and suggestions for improvements
b.) Develop and implement a statewide FM loaner system	• EITA project manager	Current	On-going	# of FM systems loaned Solicit feedback on usefulness from audiologists and families and suggestions for improvements
c.) Update the publication for families “Getting Started” that is required to be given to each family of a child with hearing loss	• EITA project manager	Current	On-going	Solicit and utilize feedback from parents, EI providers and Department of Health Newborn Hearing Screening Advisory Group..

4.3 Objective : Update, implement and analyze an annual statewide parent satisfaction survey

Activity	Responsible party	Start	End date	Evaluative measure
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a) Conduct parent satisfaction survey annually	<ul style="list-style-type: none"> <li>EITA project manager</li> </ul>	Current, annually	On-going	Number and percentage of surveys successfully returned
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	<ul style="list-style-type: none"> <li>EITA project manager</li> </ul>	Annually	On-going	Improved satisfaction rating with families Comparisons across years
4.4 Objective: Utilize the state Early Intervention Data system to compare information with the Department of Health in both retrospective and quarterly comparisons.				
Activity	Responsible party	Start	End date	Evaluative measure
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.	<ul style="list-style-type: none"> <li>EITA project manager</li> </ul>	Annually	On -going	Establish baseline data to use to compare the annual numbers of infants identified by the Department of Health and those who received an evaluation and services as recorded in the state Early Intervention Systems Compare data from 2009 and subsequent years to measure improvement and target technical assistance
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.	<ul style="list-style-type: none"> <li>EITA project manager</li> </ul>	Quarterly starting in 2012-13	On going	Analyze data from each quarter to measure improvement and target technical assistance

<b>5. Goal: Implement and evaluate the family support program Hands and Voices Guide By Your Side of Pennsylvania</b>				
5.1 Objective: Reduce the number of infants lost to follow up by having trained Parent Guides assist in follow up.				
Activity	Responsible party	Start	End date	Evaluative measure
a) Provide unbiased information and support to interested families	<ul style="list-style-type: none"> <li>EITA project manager and GBYS manager</li> </ul>	current	ongoing	# of families who request services and are served Amount and type of service provided
b.) Provide outreach to hospitals, agencies and programs	<ul style="list-style-type: none"> <li>GBYS manager and staff</li> </ul>	Current	ongoing	# of outreach events # of participants at event Types of events (meeting, conference etc.)
c.) Provide a Guided Family Notebook to all families who receive GBYS services and a Care Coordination Binder	<ul style="list-style-type: none"> <li>GBYS manager and staff</li> </ul>	Current	ongoing	Parent Satisfaction and staff surveys for suggestions for additions/improvement
d.) Evaluate the program	<ul style="list-style-type: none"> <li>EITA project manager and GBYS manager</li> </ul>	2012-13	Ongoing annually	Evaluate parent satisfaction, costs of providing support, utilization of staff, types of support requested (face to face, over the phone), effectiveness of data base to produce reports.

### **Resolution of Challenges**

Staff for the Pennsylvania newborn hearing screening program consists of a Program Manager, a Program Administrator, and three Community Health Nurses who track referrals and work with parents, physicians, audiologists and others. All of these positions are funded by the Title V Maternal and Child Health Block Grant. Currently the Program Manager position is vacant but plans are moving forward to fill that position. Also, in past years funding for many program activities including grants to hospitals, meetings, travel, etc. were funded by a state appropriation for the newborn hearing screening program. On January 18, 2011, Tom Corbett was inaugurated into office as governor for the Commonwealth. As many other states are experiencing, Pennsylvania is under severe budget constraints. In the budget for state fiscal year 2011 – 2012, all state funding for the Newborn Hearing Screening Program was eliminated. In these difficult budget times, the new administration is focusing on direct care to the public and is moving away from infrastructure building, education and prevention programs. The expectation

is that federal funding should maintain the program services currently provided by the Department staff for follow-up, data analysis, screening and technical support. Some newborn hearing screening program activities that were previously funded through the state budget are now being funded by the Title V Maternal and Child Health Block Grant; and, other activities have either been reduced or eliminated. Program is still working through solutions on funding issues.

### **Evaluation and Technical Support Capacity**

The newborn hearing screening program is housed in the Pennsylvania Department of Health, in the Bureau of Family Health's (BFH) Division of Newborn Screening and Genetics. The BFH has the support of a large body of professionals and parent advocates, as well as the experience to accomplish the goals of this grant. The Bureau has been successful in the planning, development, implementation and evaluation of diverse maternal and child health programs targeting the broader population of children and their families, including a newborn screening and follow-up program for 6 inherited genetic disorders and as of July 1, 2009, 22 additional disorders. The Department's newborn hearing screening program began in 1999 as a pilot project in 26 birthing hospitals. The project proved the practicality of implementing newborn hearing screening as a statewide standard of care for newborns. PA's IHEARR Act (Act 89 -2001) passed in November 2001 with an implementation date of July 1, 2002. The Act provides for universal newborn hearing screening in the state's 104 birthing hospitals and a comprehensive follow-up, outreach, reporting and Early Intervention referral program within the Department.

The below listed professional staffs are available to concentrate on this program (resumes are attached):

- William Cramer, Director, Newborn screening & genetics (15% effort)
- Position Vacant, Program Manager, Newborn Hearing Screening Section
- Arthur Florio, UNHSI Program administrator (100% effort)
- Keith Koppenhaver, RN, UNHSI Nurse Consultant (100% effort)
- Angela Collins, RN, UNHSI Nurse Consultant (100% effort)
- Frank Berkoski, RN, UNHSI Nurse Consultant (100% effort)

The above mentioned nursing services consultants conduct follow-up and tracking activities for newborns referred to the program. .

In addition to our staff at headquarters, there are twelve community health nurses located throughout the state in the Department's six district offices. These nurses are utilized for our hard to locate families. If there is no phone number or a disconnect number for the families and the primary care physician is incorrectly identified on the referral to program, one of the community health nurses will attempt to locate the parents and do a home visit to encourage the family to get the child a second screening or diagnostic exam. Additionally, community health nurses can assist the family in applying for health care coverage and provide information on where families can get their children screened and connect them with transportation resources if needed.

Part of the provisions of Act 89-2001 established the Infant Hearing Screening Advisory Committee. This six-member committee appointed by the Secretary of Health is to advise the Secretary and make recommendations on issues relating to, but not limited to, program regulation and administration, diagnostic testing, technical support and follow-up. The members of the committee serve without compensation; however their travel expenses are reimbursed. The committee provides a wealth of expertise to the Department in carrying out the newborn hearing screening program. Meetings are held on a quarterly basis in Harrisburg. Current membership includes two audiologists; two physicians; the director of a school for the deaf and hard of hearing; and, one parent who has two young children with hearing loss. Advisory Committee meetings have large stakeholder presences which include regular representation from: PA AAP; Part C, EI programs; the Hospital and Health System Association of Pennsylvania (HAP); Alexander Graham Bell Association; the schools for the deaf; and the Office of Deaf and Hard of Hearing.

There are several levels of evaluation incorporated into the activities of the program and this grant. All of the activities involving hospital reporting include regular monitoring of monthly hospital reports and individual referrals. Both the program administrator and the three nurse consultants will note any discrepancies and provide feedback to the hospitals in an organized manner. For activities that involve physician education, program is relying on our vendor, the PA Chapter of the American Academy of Pediatrics (PA AAP), to provide feedback from the web-based training curriculum and feedback from technical assistance to the Department to make improvements to program services provided to primary care physicians (PCP). Additionally, program staff will monitor communications with PCP offices and note any concerns with communications and information received. Follow-up with PCP offices will be provided by PA AAP when program staff efforts are ineffective. Lastly, our projects with early intervention have several evaluation components. Annual parent surveys provides feedback on the both the newborn hearing screening program and the Early Intervention system. Trends identified through these surveys will be utilized to shape future training topics. Training evaluation results will be shared with the Department to determine the effectiveness of the trainer. Training participants will complete a training needs assessment that will shape the topics for future EI workshops. Reviews of Individual Family Service Plans will be conducted by EI professional staff on an annual basis to determine if the training materials were absorbed and utilized correctly. This information will be shared with the Department along with recommendations for corrective action and next steps to improve service coordination. Families participating in Guide by Your Side will complete surveys and the results will be shared with the Department and with the Advisory Committee to help shape and improve the PA Guide by Your Side Program.

## **Organizational Information**

The Pennsylvania Department of Health's Bureau of Family Health houses the Newborn Hearing screening program in its Division of Newborn Screening and Genetics. The Department's and Bureau's organizational chart are attached (Attachment 1). The Department is divided into Deputates. Each Deputate is divided into Bureaus, each Bureau into Divisions and each Division is separated by section. The Bureau of Family Health's mission is to promote and protect the health of pregnant women, infants, children and children with special health care

needs and their families through education and health promotion, food benefits and access to quality health care. The Bureau of Family Health houses numerous programs such as the Women, Infants and Children's Program (WIC), Childhood Lead Poisoning Prevention Program, Special Kids Network Helpline, System of Care for Children with Special Health Care Needs, Medical Home Program and the Newborn Bloodspot Screening Program. Each of these programs support the families involved in the newborn hearing screening program.

Act 89 of 2001 mandates the Department of Health to establish a program that includes a system to screen all newborns for hearing loss before leaving the hospital, screen all newborns that are not born in a hospital within the first 30 days of life and provide information to parents on the benefits of screening and follow-up care. The Department is also charged with administering the program and with providing technical support to health care facilities and others. A parent may refuse the screening for any reason and it should be documented in the child's medical record and reported to the Department. Screening is required for a minimum of 85% of infants born in the state and if the percentage screened falls below this minimum the Department in consultation with the advisory committee must promulgate regulations to implement a state-administered hearing screening program. Since the program's inception, screening rates have exceeded 90%; therefore, there are no regulations. The Department, in conjunction with the advisory committee, developed program guidelines for the administration of the program for in and out-of-hospital birth settings. A reporting component is also required in the legislation as well as a referral system to early intervention.

## **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
- e. Primary Contact Information:
  - i. Name and Title: Luann Cartwright, Program Manager
  - ii. Phone: 717-547-3335
  - iii. Email: [lcartwright@pa.gov](mailto:lcartwright@pa.gov)

## **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.