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). Since that time the program has evolved into a unique system of intra- and inter-governmental organizations, stakeholders and professionals hosting a seamless system of services for infants screened through newborn hearing screening. 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, improved communication, quality improvement and technical assistance.

Needs Assessment

Pennsylvania is a Mid-Atlantic state with a population of 12,448,279 (2008 US Census estimate). There are 67 counties and 48 of those counties are rural. Approximately one-third of the population resides in rural areas of the Commonwealth, which makes hearing screening for out-of-hospitals births a concern. 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 2007 there were 150,001 occurrent births in Pennsylvania; 146,196 were hospital births and 3,805 were out-of-hospital births. There were 123 birthing hospitals in the Commonwealth in 2007 all with a Newborn Hearing Screening Program. The average referral rate in 2007 was 1%. Approximately 18 hospitals, in 2007, had a referral rate above 2%. Of those 18 hospitals only 9 had a referral rate above 4%. Hospitals that have unusually high or low referral rates are connected with the technical assistance component of the program. As of the writing of this report, there are 112 birthing hospitals in Pennsylvania.

Most infants that are referred to the Department for follow-up have a primary care physician listed on the referral form. These physicians are confirmed by letter as well as phone calls and faxes to the practice for follow-up information. In 2008, a mail survey of all licensed audiologists was conducted requesting responses from audiologists treating infants and children starting in the newborn period. Seventy-nine responded and self identified as treating infants and toddlers. Information for these audiologists will be organized into a database and shared via a new hearing screening statewide website.

In 2007 143,568 infants completed hearing screenings (142,383 hospital births and 1,185 out-of-hospital births). 1,383 infants did not pass a first and second screening. Of those infants that did not pass, 711 were later diagnosed with normal hearing, 154 were diagnosed with a permanent hearing loss, 118 were diagnosed with a non-permanent conductive hearing loss, 6 expired, 158 parents declined services, 16 moved out of state and 220 were lost to follow-up (20%). Of those 220 that were lost to follow-up, the Department received no information on 135 of those cases and received documentation on 85 of those cases. Of the 85 cases were the Department received documentation, 49

were lost to follow-up after the initial screening, 34 were lost after the follow-up screening and 2 were lost after receiving an inconclusive diagnostic audiological evaluation.

As referenced in the data above, the largest portion of the lost to follow-up cases the Department received no documentation that the child failed a screening. Birthing hospitals in Pennsylvania conduct the hearing screening in the hospital before the infant is discharged. The hospitals report the total number of infants born, screened, passes and fails in aggregate form on a monthly basis to the Department of Health. Infants that do not pass an initial screening are screened again. Some hospitals do the follow-up or second screening before discharge; some conduct the screening in an outpatient setting. Infants that fail an initial screening and fail a second screening or do not show up for their outpatient screening appointment should be referred to the Department of Health for follow-up. These referrals contain individual information on the infant, including name, date of birth, primary care physician's name and contact information and parent's name, addresses and phone numbers. This critical information is the Department's only means of locating this infant for follow-up. A main focus of our work during the next three years is to improve the quantity and quality of the referrals received from hospitals.

For the out-of-hospital birth population, the Department provides screening equipment to 15 individual midwives and the 5 licensed birthing centers in the state to conduct hearing screening. The majority of these families refuse the screening, on the basis of cultural or religious reasons. The infants are usually screened at the post-partum visit and not at birth; therefore, few fail the screening. The midwives report the total number of infants born, screened, passes and fails in aggregate form on a monthly basis to the Department of Health. Those that fail are reported to the Department in the same manner the hospitals report, individually with the aforementioned contact information for the family and PCP. Additionally, follow-up with these families is a unique experience. Many of these families do not have a primary care physician or phone, so our only contact with the families is through the midwives and the mail. The Department's relationship with our midwife network is invaluable to identifying these infants and encouraging the diagnostic process.

Following the initial referral from hospitals, midwives or birthing centers, the majority of cases were lost because the primary care physician listed on the referral form was incorrect and the parent's phone number was disconnected or they moved with no forwarding address. This was true with both the initial screenings and the follow-up screenings. There was no evidence that families received a diagnosis and were lost to follow-up at entry into early intervention.

Methodology

This application will discuss our plan to reduce loss to follow-up rates over the next three years through education, improved communication, quality improvement and technical assistance

Education, technical assistance and improved communication are intertwined in our efforts to work with our hospitals, midwives and birthing centers to improve the quantity of referrals submitted to the Department. Our goal is to improve data collection methods to ensure the screening status is reported on all infants that fail the newborn hearing screening. Currently, monthly aggregate reports are completed manually by the hospital or midwife and emailed or faxed to the program administrator. The program administrator reviews the reports for possible reporting errors; works with the submitters to correct any identified errors and then enters the information from each hospital or midwife into an excel spreadsheet. Individual referrals for infants that fail the hearing screening are completed manually and faxed to one of the Department's three nursing services consultants. The nursing services consultant attempts to locate the infant's bloodspot screening results in the Department's Newborn Screening data system and then manually enters the hearing screening information into the record.

The nurses record all of their contacts with the PCP and/or family in the contact notes of the system. They also create letters to the family and PCP as well as record the screening results and the diagnostic test results in the system. Unfortunately, the data system is flawed and will open and close cases at will as well as create duplicate cases, making accurate automated counts unreliable. To compensate for these issues, program staff enters information in multiple locations. A spreadsheet of all infants identified with a hearing loss is kept along with entering the information into the data system. Paper records are also kept for two years and filed by the cases' endpoint. Program is gradually moving towards electronic reporting. The Department has been in a multi year research process to determine the needs of the program as well as find a suitable data system solution for both the hearing screening program and the bloodspot screening program. One of the requirements of the new data system is that it will be able to upload screening data from the hearing screening units in the hospitals and in the midwife network. This will eliminate much of current manual reporting burden on both entities. Additionally, program has been working with the Bureau of Health Statistics and Research and has been pilot testing the addition of hearing screening results in the electronic birth certificate reporting system. Eventually, the birth certificate information will be uploaded into the new newborn screening data system and program will have access to initial hearing screening results for all infants as well as demographic information that is currently inaccessible.

A second component of the referral issue is the turnover of staff in both hospital screeners and in hospital newborn hearing screening coordinators. When staffs change, program information is lost and practices that were once automatic are no longer completed. This training and awareness component will improve relations with our hospital stakeholders through the formation of a hospital work group. This group consists of eight hospitals. The selected hospitals are geographically dispersed throughout the Commonwealth; represent both rural and urban areas; and, have both larger and small numbers of births. This is the first formal communication the program has initiated with the hospitals since the inception of the program. The Department is looking into forming a similar workgroup with our participating midwives for the same purpose. The hospital workgroup will collaborate with the Department on the information they recommend

sharing with all hospitals through an annual mailing as well as developing an agenda for an annual hospital teleconference so all birthing hospitals can connect with the program and discuss policies and procedures.

In order to reconcile the incoming referrals with the monthly aggregate report of failed screens, program staff will monitor the reports and referrals for consistency. Hospitals that show a higher number of infants that fail the screening on aggregate monthly reports then the number of referrals received will be contacted through our technical assistance vendor the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP). Our vendor will work one on one with the hospitals to discuss their screening protocols and reporting procedure to clarify any areas of concern. The Department will then monitor that hospital following the technical assistance contact, to determine if improvements have been made.

Next, the Department plans to improve the quality of the information that is reported to the Department to increase the probability of finding families and connecting them, after the initial screen, with follow-up screenings and services. UNHSI staff had the opportunity to participate in the first National Initiative for Children's Healthcare Quality (NICHQ) collaborative in 2006-7 that focused on improving follow-up by working through the Medical home. Multiple strategies were studied and tried in Pennsylvania, some successful that will be discussed later. One strategy that was studied was the accuracy of family and primary care physician's contact information and its effect on loss to follow-up. The Department's referral form used by hospitals, midwives and birthing centers needs to be redesigned to improve the quality of data provided to the Department. Program plans to continue with this effort that began during the NICHQ collaborative and move forward with the design changes. A second family contact will be added to the form, as found to be successful in our collaborative. Additionally, more identifying information will be requested and some terminology will be simplified to provide clear instructions to the individual completing the form. The importance of the correct information on the referral forms will also be discussed with the hospital workgroup to get some suggestions of best practices that can be shared. Lastly, program will work with the PA AAP our technical assistance vendor to identify hospitals that regularly submit incomplete information and provide education and assistance in a one on one setting.

Previously, in June 2008 DOH and PA AAP developed a hospital newborn hearing screening survey asking for information on the hospital's initial and follow-up hearing screening procedures as well as asking how hearing screening results are communicated to PCPs and the state EHDI Program. PA AAP has been gathering information for the questionnaire by telephone calls to the 10 largest birthing facilities who account for approximately 31% of all hospital births. (Additionally, technical assistance/consultation is provided for any situations that come to light during the phone discussion.) Initial results gathered from the questionnaires were reviewed by DOH and the Infant Hearing Screening Advisory Committee at a meeting in March 2009 and a further review will take place at a meeting scheduled for June 2009. Plans are to use the results from the questionnaire to develop and publish a "Hospital Newborn Hearing Screening Best Practices" document in conjunction with the hospital workgroup and the Infant Hearing

Screening Advisory Committee. During the past year PA AAP continued to provide technical assistance; one example of assistance provided is Robert Cicco, MD and PA AAP Chapter Champion, contacted Onsite Neonatal Partners to resolve newborn hearing screening reporting issues for Riddle Memorial Hospital, Mercy Suburban Hospital, Chester County Hospital and Ephrata Community Hospital where Onsite is contracted to provide hearing screening for newborns.

Many of the efforts listed above will positively impact the lost to follow-up rates experienced after the second hearing screening. However, through our research during the NICHQ collaborative, there are specific focus areas relating to Primary Care Physicians (PCPs). Most of the lost to follow-up cases could not be located due to an incorrect PCP or incorrect family contact information. Additionally, there were many PCP offices that did not communicate to the Department when information was requested. In an effort to improve relations with our PCPs we send a copy of the letter sent to the parents to the PCP and include a rack card with our web-based training, On-Line-EHDI. Also, as our nursing services consultants speak with PCP offices they offer to send them a copy of the program guidelines, this is a new practice that began in Summer 2008. Since that time, 70 packets have been distributed to PCP offices. Our nurses have found that offices receiving the guidelines were more receptive to our requests for information.

In mid-2006 a web-based continuing medical education resource for physicians, known as On-Line Early Hearing Detection and Intervention (On-Line EHDI) was introduced. This resource was developed by two physicians at the University of Pittsburgh, under the guidance of the PA AAP and the PA Infant Hearing Screening Advisory Committee. The online training consists of four case studies with different contingencies—two of children suspected of having early childhood hearing loss, one of a child already diagnosed with profound hearing loss and another of a child with a suspected late onset hearing loss. Each module includes a list of informational resources and completers are eligible to receive Continuing Medical Education Credits (CMEs). On-Line EHDI is especially useful for the PCPs of newborns who do not pass their hearing screening. To publicize the program to physicians, DOH sends a letter and/or e-mail to physicians who have a newborn in their practice with suspected or diagnosed hearing loss that explains how On-Line-EHDI can be useful in providing them with information about critical follow-up testing and care, and vital information of interest to parents.

PA AAP has also marketed On-Line EHDI to PCPs via a mailing to pediatric chairs of birthing hospitals and pediatric/family practices, and with an announcement link on its own website. In 2008 work began on the development of two new case studies that will further enhance primary care physicians' knowledge of newborn hearing loss and the role a primary care physician plays in providing timely referrals to audiologists, appropriate specialists and early intervention services as well as counseling families of a child diagnosed with hearing loss. The new cases will take an in-depth look at: 1) a NICU patient with auditory neuropathy; and 2) an infant who passes newborn hearing screening but whose parents express concerns with the child's hearing at the 4-month visit. Finally plans are being developed to use On-Line-EHDI to educate pediatric and family practice

residents. Two case studies will be developed to increase the understanding of 1) the importance of EHDI; 2) how hearing loss is detected, diagnosed and treated; 3) the risk factors associated with hearing loss; and 4) the long-term impact of hearing loss. These case studies will be developed using real-life scenarios and include the use of practice tools and resources for families. Additionally, two presentations will be made each grant year (2009-2010 and 2010-2011) to pediatric and family practice resident groups using the On-Line-EHDI case studies as an interactive educational tool.

In our physician letters we started to include our parent roadmap that was created during our NICHQ collaborative. This component was part of an audiology brochure that was never published. We redesigned the roadmap onto a single sheet and include it in the parent letter. We found that parents were providing the roadmap to the physicians and it was made part of the patient's record. Additionally, we regularly send out by email or regular mail copies of our program guidelines. As with hospitals, physician offices change staff and may not be familiar with the program if they do not serve many young children with hearing loss.

In July of 2003 under a contract with the PA Chapter of the American Academy of Pediatrics (PA AAP) the PA UNHSI program launched an educational outreach effort known as EPIC-EHDI (Educating Physicians in their Community – Early Hearing Detection and Intervention). The target audience of the program is: (1) primary care physicians (pediatricians, family practitioners, obstetricians and gynecologists); (2) hospital physicians and professional staff responsible for administering newborn/infant hearing screening in birthing facilities; (3) university-based and academic institution medical and professional staff; (4) audiologists; and (5) nurses, nurse educators, nurse-midwives and childbirth educators who provide birthing services and classes at prenatal clinics. The aim of this program is to reduce losses to follow-up by linking children with suspected or identified hearing loss to coordinated care through early identification of a Medical Home (MH). The program is packaged under PA AAP's successful EPIC physician education model, which incorporates the MH concept into key aspects of its outreach strategy, including teleconferences, presentations, multimedia web-based learning, technical assistance, and printed materials.

Under this program, a teleconference for pediatric audiologists was presented by Judith Gravel, PhD, CCC-A, Director of the Center for Childhood Communication at the Children's Hospital of Philadelphia on June 10, 2008. Dr. Gravel's presentation was entitled "JCIH 2007: An Update for Pediatric Audiologists". There were a total of 30 audiologists from across Pennsylvania participating in the teleconference along with 12 audiology students from Bloomsburg University.

A "Let's Talk" teleconference entitled "Late-Onset and Progressive Hearing Loss" was presented by two nationally known experts on November 18, 2008. The presenters were Arti Pandya, MD, who is an Associate Professor in the Department of Genetics at Virginia Commonwealth University and is an expert on genetics and hearing loss; and, Karen Fowler, Ph.D. who is a Research Associate Professor in the Department of Pediatrics at the University of Alabama at Birmingham and is an expert on CMV. Robert

Cicco, MD, a neonatologist at Western Pennsylvania Hospital, served as moderator. The objectives of the teleconference were for participants to be able to: 1) Describe and implement an effective Early Hearing Detection and Intervention (EHDI) system that includes the monitoring and diagnosis of late-onset and progressive hearing loss; 2) Describe the risk factors associated with late-onset and progressive hearing loss; 3) Understand CMV as a main risk factor for late-onset and progressive hearing loss; and, 4) Understand the genetic components of late-onset and progressive hearing loss. Participants were eligible for 1 continuing medical education (CME) credit or 0.1 continuing education units (CEU). There were a total of 46 participants representing 11 practices and 21 of the participants were primary care physicians.

Amie Gordon-Langbein, DO, a family practitioner from Bucks County, presented a session on EHDI at the Pennsylvania Osteopathic Medical Association annual conference in Valley Forge on May 2, 2008. Approximately 80 pediatricians and family practitioners were in attendance and feedback was very positive. All participants received an information packet with AAP's Universal Newborn Hearing Screening, Diagnosis, and Intervention Guidelines for Pediatric Medical Home Providers; a Patient Checklist for Pediatric Medical Home Providers; and, a Hearing Screening Coding Fact Sheet for Primary Care Providers as well as an On-Line EHDI brochure and a Communication Options chart from Beginnings Program in North Carolina.

While our data does not show a definitive loss to follow-up for infants diagnosed and lost before enrolling in early intervention, we know one exists simply by comparing the number of identified children in our records with the total number of children enrolled in early intervention with a hearing loss. Our goal is to reduce the number of infants that are lost to follow-up at this point in the process by providing appropriate early intervention services and family support. In September 2007, under a contract with the Tuscarora Intermediate Unit Early Intervention Technical Assistance (EITA), PA's UNHSI Program launched a three year effort to strengthen and enhance early intervention services for children with hearing loss. Major activities undertaken to reach this goal include education workshops to inform early intervention providers (local service coordinators, provider staff, Head Start and selected early child care staff) on topics necessary to build their professional skills; development of a web-based/multimedia training course that encompasses the topics covered in the education workshops; the design and distribution of a satisfaction survey for families of children with hearing loss enrolled in early intervention services; support of Summer Institutes on Hearing Loss in Infants/Toddlers for parents and early intervention staff; administration of a scholarship program for parents to attend this Summer Institute; and, a plan to update and increase the number of loaned resource material kits available to Part C, early intervention service coordinators, teachers, and others working with infants and toddlers identified with hearing loss. Lastly, the beginning of a small scale Guide by Your Side family support program is in the planning stages and moving to the implementation stage.

In May 2008, EITA held a statewide training workshop titled, "Good Starts for Babies with Hearing Loss and Deafness". The workshop was presented by Ms. Mary Koch, an auditory education consultant with a Masters in Education of the Deaf from Gallaudet

University. This workshop provided an overview of communication and language considerations for babies and infants who are deaf and hard of hearing. In the workshop, Ms. Koch reviewed choices for various communication and language options and described strategies for working with newly identified babies and infants with hearing loss and their families. Information and strategies for monitoring children with cochlear implants and hearing aids was also provided. A total of 336 individuals attended the workshop including 53 early intervention Service Coordinators; 88 EI Special Instructors and 75 Speech Language Pathologists.

In October-November 2008, EITA held a second statewide training workshop titled, "Supporting Families of Young Children who are Deaf/Hard of Hearing". The workshop was again presented by Ms. Mary Koch. The morning session began with a review of basic audiology, including videos of different ways of screening or testing hearing in newborns, infants and young children. Ms. Koch demonstrated simulations of hearing losses with and without assistive technologies, such as hearing aids and cochlear implants, on a website that can be accessed without cost by anyone. She also provided several different ways of explaining to families the array of communication options for families of children with hearing loss. Finally, she shared a slide presentation from national Hands and Voices stressing the importance of presenting unbiased information to families. The afternoon session was dedicated to a "resource fair" which included at least six speakers. Speakers included individuals who are hearing, hard of hearing and deaf. The National Institute on Deafness and Other Communication Disorders (NIDCD) supplied attendees free copies of their 2008-09 Resource Directory. Guest speakers provided additional content for the "resource fairs." Each presenter spoke about him/herself as an individual with deafness or hearing loss, as a parent, or as a representative of a specific agency or organization. Speakers included representatives from: the Office for the Deaf and Hard of Hearing/ODHH; the Pennsylvania Deafblind Project; Parent-to-Parent of Pennsylvania; the American Society for Deaf Children; the Hearing Loss Association of America (formerly SHHH, Self Help for Hard of Hearing People); the National Cued Speech Association; representatives from A.G. Bell Association (national and Pennsylvania chapters); and, the Pennsylvania chapter of Hands and Voices. Handouts from these and related organizations and agencies were available for participants to review and take home. Approximately 294 individuals attended this workshop including 72 early intervention Service Coordinators; 59 EI Special Instructors; and 41 Speech Language Pathologists.

In June 2008, Mary Koch recorded segments of a web-based course on "Orientation to Deafness/Hearing Loss in Infants and Young Children" designed for early intervention Service Coordinators. These segments include (1) Introduction; (2) Benefits of Early Intervention, (3) Communication and Language; (4) Modalities and Controversies; (5) Understanding Hearing; (6) Hearing Technology; (7) Early Intervention; (8) Web Resources; and (9) Review. The course includes learning objectives and activities, videotaped materials, downloadable slides and tape transcripts as well as quizzes for each segment. Pilot testing is scheduled for June 2009 and will determine the hours that are required for course completion. The course will be offered to EI service Coordinators for Infant/Toddler credit in fall 2009. A web-based database for selected programs serving

young children with hearing loss has also been in development and will be ready for use by June 2009. This database allows a sampling of 5 Infant/Toddler programs serving children with hearing loss/deafness and their families in Pennsylvania to examine their own information with respect to demographics and families' experiences in newborn hearing screening, pediatrics, audiology and early intervention. All such data can be pooled to provide feedback to the Department of Health UNHSI program on the effectiveness of the EHDI program.

In March of 2008, EITA distributed a "parent satisfaction" survey to families of children with hearing loss who were currently enrolled in early intervention services. The major purpose of this survey was to assess whether parents were informed about the full range of communication options and were linked in a timely way with appropriate EI services. A total of 326 surveys were mailed and EITA received 123 completed surveys for a response rate of 38%. A list of several major findings from this survey appears below:

- 90% of the respondents reported that, "My child was first seen by audiologists before they were six months old."
- 70% of the respondents reported that, "My child entered EI Services by the time they were six months old."
- 95% of the respondents reported that, "In early intervention I was given access to at least one person who is qualified in the areas of deafness or hearing loss."
- 98% of the respondents reported that, "In EI, 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."
- 95% of the respondents reported that, "I am satisfied with the level of knowledge and professionalism of my EI service coordinator".

A Low Incidence Institute was held in State College in August 2008. This meeting focused on topics related to serving young children and students with deafness and hearing loss, deaf blindness, blindness, visual impairment, mental retardation, and multiple disabilities. Attendees included parents who have children with hearing loss, speech and language clinicians, audiologists, educational sign language interpreters, consultants, service coordinators, and administrators working with students with deafness and hearing loss. Eileen Rall, Senior Audiologist, Center for Childhood Communication at Children's Hospital of Philadelphia represented Judith Gravel, Ph.D., and presented at the Institute on behalf of the PA UNHSI Program. Her presentation included information concerning: (1) an overview of the Pennsylvania UNHSI Program with updates on both Pennsylvania and national newborn hearing screening efforts; (2) current technologies available for comprehensive hearing assessment in children from birth to age five; (3) an update on prescriptive amplification fitting; (4) current hearing aid technologies; (5) FM systems; (6) an update on cochlear implant (CI) technologies, current candidacy criteria, sequential bilateral implant candidacy and criteria, and FM considerations for young CI users; and (7) intervention considerations. Through the contract between EITA and DOH, eight parent scholarships were provided to reimburse parents for travel expenses when attending the Pennsylvania Low Incidence Institute.

Pennsylvania's Training and Technical Assistance Network/PaTTAN, of which EITA is a part, administers a Short Term Loan Kit library consisting of both assistive technology and resource materials which are made available to EI staff upon request. Common items found in the kits include books, toys, videotapes, DVDs, CDs, workbooks and text books. Under the contract between DOH and EITA the number of kits available has been increased and materials in the kits have been updated. Information and resources available cover a wide range of topic including information about early language development, auditory tests, signing videos and books, early literacy, an overview as well as detailed materials concerning communication methodology options, videos on best practices in home visiting and early intervention and others. Short Term Loan Kit library materials continue to be developed now that some loans have been made.

In 2007, the Newborn Hearing Screening Program contracted with Pennsylvania Training and Technical Assistance Network (PaTTAN), Early Intervention Technical Assistance to develop and implement outreach tools to inform early intervention provders on topics necessary to build their professional skills to educate children with hearing loss and their families in methods of communication. Also through this contract, the Deparment wanted the vendor to provide support and information to families of young children with confirmed hearing loss. The vendor accomplished this by researching the needs of families through a parent satisfaction survey of all families that have a child with hearing loss enrolled in early intervention and asking questions related to their experience with the newborn hearing screening system, early intervention and support in general. This survey in 2008 indicated a significant need and lack of resources in the area of family support.

The Infant Hearing Screening Advisory Committee has also been discussing and researching the issue of family support for several years. The committee has reviewed the Guide by Your Side Program, that is trademarked by Hands and Voices, and strongly agrees with its concept and mission of providing unbiased information on communication methods in a non-invasive manner. Additionally, at the September 2008 committee meeting a Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis was conducted and, our members and stakeholders clearly indicated lack of a family support effort as a weakness in our program.

The Guide by Your Side program is a known successful program that will bring Pennsylvania in line with other states in our efforts to educate families through the process of hearing loss and intervention. The Guide by Your Side Program is a peer support program for parents of children with hearing loss. The "guides" are parents that are paid and trained on the multitude of communication options available for families that have a child with hearing loss. The "guides" are parents of a child identified with hearing loss; they can share their experiences and present the communication options to families in an unbiased manner. This option will be offered to families that have a child recently identified with a hearing loss that may be considering the services of early intervention.

The service will reduce our loss to follow-up rates for those families that do not make the connection to early intervention. The program will assist families in gaining honest, unbiased information in a supportive informal manner. Additionally, there is an

evaluation component to the program. Each parent that participates in the program will be required to complete a satisfaction survey. The Department will work with early intervention Technical Assistance to develop performance standards and specific deliverables within their contract to ensure the program is successful in a measurable way.

In April of 2008, PA EHDI Program staff began a discussion with William Eiserman, PhD, from the National Center for Hearing Assessment and Management (NCHAM) on the possibility of starting an OAE Early Head Start Hearing Screening Program in Pennsylvania. It was believed that a well structured OAE Early Head Start Hearing Screening Program would help reduce losses to follow-up in the state EHDI Program; and, helps identify young children who develop late onset hearing loss.

Eight Early Head Start Programs were identified and agreed to participate in launching an OAE Early Head Start Hearing Screening Program in Pennsylvania; and, programs were then matched with a local audiologist who specialize in pediatric care. This group formed the initial Pennsylvania Early Childhood Hearing Outreach (ECHO) team. Although selected programs are located throughout the state, most programs are located in the Southeastern region which historically has the greatest number of EHDI lost to follow-up cases.

In October 2008 Dr. William Eiserman and two members of his staff traveled to Harrisburg to conduct a training session with representatives from the eight programs; with audiologists who were partnered with each program, with PA EHDI program staff and a DOH Community Health Nurse. NCHAM provided six Early Head Start Programs with a free OAE hearing screening unit and supplies that were distributed at the training – (Luzerne County had already purchased their own unit; and, the Berks and Chester County programs agreed to share a unit). After a two-hour classroom training, the attendees divided into three groups and visited three local Early Head Start Programs for hands-on training with the new equipment. All program representatives agreed to begin screening and to report screening results by February 2009.

On March 6, 2009 Mr. Eiserman and PA EHDI Program staff had a teleconference with PA ECHO team members to answer questions and to offer assistance. PA EHDI staff is currently working with ECHO teams to develop a system to report information to the EHDI Program when children are identified with permanent childhood hearing loss. Also, ECHO team members are now on a PA EHDI Program distribution list and will routinely receive general information that may be of interest or benefit to them.

1.0 Goal: Improve data collection methods to ensure screening status is reported on all infants failing the newborn hearing screening				
1.1 Objective: Improve communication with hospitals and midwives to encourage and monitor reporting of all infants that fail the newborn hearing screening				
Activity	Responsible party	Start date	End date	Evaluative measure
a) Acquire a data system capable of receiving electronic screening data	• DOH program staff • DOH procurement staff	Fall 2006	Fall 2010 (latest go-live date)	Successful go-live launch and transition of data.
b) Review hospital monthly reports and compare failed screen numbers to referral numbers, refer for technical assistance when discrepancy indicated	• DOH program administrator • PA AAP project manager • DOH nurse consultants	Spring 2009	On-going (monthly)	The number of failed screens and referrals reported to DOH on a monthly basis are consistent
c) Conduct site visits to network midwives participating in the Out-of-Hospital Hearing Screening Program	• DOH program staff	Spring 2009	On-going (annually)	Improved reporting of screenings conducted, referrals would include complete information and fewer families would refuse the screening.
1.2 Objective: Provide formal feedback to hospitals on facility statistics				
Activity	Responsible party	Start	End date	Evaluative measure
a) Modify CDC survey spreadsheet to include hospital name for children identified with a hearing loss	• DOH program administrator • DOH nurse consultants	January 2009	Ongoing	All children identified with a hearing loss on the CDC survey spreadsheet will have the name of their birth hospital listed.
b) Send a copy of the annual General Assembly report to	• DOH program administrator	Summer 2009	Ongoing annually	Feedback from hospitals on mailing with an informal survey.

all birthing hospitals	• DOH clerical support staff			
c) Host an annual conference call to update all birthing hospitals on program changes and provide feedback on facility participation	• DOH program manager • DOH program administrator • DOH nurse consultants	Summer 2009	Ongoing annually	Feedback from participants about the conference call with an informal survey.
1.3 Create a hospital workgroup to suggest and test changes, recommend best practices and provide input on policy issues				
Activity	Responsible party	Start	End date	Evaluative measure
a) Solicit interested birthing hospitals	• DOH program administrator	Fall 2008	January 2009	Assembled list of hospitals that are willing to participate and represent a cross-section of types
b) Host first conference call and review information bulletins, NCHAM training video & PCP survey data	• DOH program administrator • DOH program manager • PA AAP project manager	March 2009	March 6, 2009	Feedback from participants on the conference call through an informal survey.
c) Maintain hospital workgroup through regular email communications and quarterly conference calls	• DOH program administrator	March 2009	Ongoing	Regularly scheduled calls and informal feedback on the discussions during the calls.
2 Goal: Reduce the number of infants lost to follow-up after initial screening through improved data quality on referral forms				
2.1 Objective: Redesign referral form to improve data quality.				
Activity	Responsible party	Start	End date	Evaluative measure
a) Add a second family contact	• DOH Program staff • Hospital workgroup	Fall 2006	Spring 2009	Fewer families are lost to follow-up due to incomplete or incorrect information on the referral form.

	• Advisory Committee			
b) Simplify instructions	• DOH Program staff • Hospital workgroup • Advisory Committee	Fall 2006	Spring 2009	Fewer families are lost to follow-up due to incomplete or incorrect information on the referral form.
c) Get input from hospital workgroup and advisory committee	• DOH Program staff • Hospital workgroup • Advisory Committee	Spring 2009	Summer 2009	Fewer families are lost to follow-up due to incomplete or incorrect information on the referral form.
2.2 Objective: Provide technical assistance to hospitals that demonstrate high lost to follow-up rates to improve data collection methods				
Activity	Responsible party	Start	End date	Evaluative measure
a) Discuss screening protocols with hospitals	• PA AAP managing physician • DOH program administrator • PA AAP project manager	Current	On-going	Lost to follow-up rates for specific hospitals decrease and data quality on referral forms improves.
b) Clarify issues observed at the Department	• DOH program administrator • PA AAP project manager • PA AAP managing	Current	On-going	Lost to follow-up rates for specific hospitals decrease and data quality on referral forms improves.

	physician			
c) Provide best practice suggestions from assembled information from hospital workgroup	• DOH program administrator • PA AAP project manager • PA AAP managing physician	Current	Ongoing	Lost to follow-up rates for specific hospitals decrease and data quality on referral forms improves.
3 Goal: reduce the number of infants lost to follow-up after second screening				
3.1 Objective: Improve communications with PCP office				
Activity	Responsible party	Start	End date	Evaluative measure
a) Discuss cases with PCP office staff and send educational information about Online-EHDI web-based training to PCPs through PA AAP newsletters and copies of patient letters	• DOH Nurse consultants • PA AAP project manager • DOH clerical support	Current	On-going	Increase number of PCP offices that respond to requests for information from DOH Nurse Consultants
b) Send PCP office staff updated program guidelines, brochures and EHDI roadmap to develop understanding of EHDI protocols	• DOH Nurse Consultants • DOH clerical support	Current	On-going	Increase the number of PCP offices that respond to requests for information from DOH Nurse Consultants
3.2 Objective: Provide educational opportunities to PCPs on the hearing screening process				
Activity	Responsible party	Start	End date	Evaluative measure
a) Host regular teleconferences on hearing screening issues	• PA AAP managing Physician	Current	On-going	Post teleconference feedback shows an increased knowledge of hearing screening process

	• PA AAP project manager			
b) Provide web-based training and free CMEs on hearing screening case studies and diagnostic protocols	• PA AAP project manager • PA AAP managing physician	Current	On-going	Review questions show an increased knowledge of hearing screening process
c) Provide at least 2 presentations annually to pediatric and family practice resident groups using the on-line EHDI case studies as an interactive educational tool.	• PA AAP project manager • PA AAP managing physician	Fall 2009	Summer 2011	Increased communication with pediatric/family practice clinics that utilize pediatric/ family practice residents.
3.3 Objective: Develop tools to improve communications between PCPs, Hospitals and DOH to ensure continuity of care				
Activity	Responsible party	Start	End date	Evaluative measure
a) Create a physician roadmap and fact sheets to assist PCPs in the diagnostic process	• PA AAP managing physician • PA AAP Project Manager • DOH Program Administrator • DOH Nurse Consultants • Advisory Committee	Fall 2009	January 2010	Increase the number of PCPs that understand the next steps in the diagnostic process and respond to requests for information from DOH nurse consultants
b) With the hospital workgroup develop an infant health summary form	• Hospital workgroup • PA AAP	Fall 2010	Spring 2011	Decrease in the number of infants with the wrong PCP listed on referral form.

for communication between hospitals, PCP offices and DOH hearing screening program	managing physician • DOH program administrator • DOH nurse consultants • Advisory Committee			
4 Goal: reduce the number of infants lost to follow-up between diagnosis and early intervention by providing appropriate early intervention services and family support.				
4.1 Objective				
Activity	Responsible party	Start	End date	Evaluative measure
a) Provide education workshops to enhance the skills of service coordinators serving families of children with hearing loss	• EITA project manager	Current, annually	On-going	Positive training evaluations
b) Provide parent scholarships to Low Incidence Institutes	• EITA project manager	Current, annually	On-going	Positive feedback from participating parents
c) Provide educational resources through short term loan kits	• EITA project manager	Current	On-going	# of kits utilized and the requests for more resources along with evaluations of kit materials
d) Create a web-based training based on the educational workshops	• EITA project manager	Current	Testing fall 2009	Pre-test vs. Post-test scores show and improved understanding of the needs of a child with hearing loss/
e) Conduct parent satisfaction survey	• EITA project manager	Current, annually	On-going	Improved satisfaction rating with families
d) Implement Guide by Your Side Program in	• EITA project manager	Spring 2009	Roll-out January 2010.	# of families served by the program annually along with the evaluation of

Pennsylvania	• DOH program staff • Advisory Committee			services from participating families

Resolution of Challenges

In September 2008, the Infant Hearing Screening Advisory Committee held its quarterly meeting in conjunction with a stakeholder meeting and planning session. During the second half of the day, a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis was conducted by the Commonwealth's Bureau of Management Consulting. Many of the challenges that will be discussed below were brought to light in the SWOT analysis session during the weaknesses discussions.

The most significant challenge in the Pennsylvania Newborn Hearing Screening program is the need for a reliable data and tracking system. Currently our program relies completely on hospital staff to hand tally all screenings completed on a monthly basis and complete individual referral forms for each child that does not pass the second hearing screening. Human error is a large concern for our program, knowing the large number of births that take place and the demands on the hospital nurses and administration; inevitably infants will be forgotten and not reported, as noted in the lost to follow-up data. The Department received no documentation for 60% of the lost to follow-up cases. Over the past 5 years the program has undergone several initiatives to develop and/or research new data systems to identify the needs of the newborn hearing screening and bloodspot screening programs as well as predict future needs of the programs. We are on the cusp of procuring a web-based system that has the capability to upload screening data from hearing screening units as well as upload birth certificate data. Eventually, the goal is to have all hospitals and pediatric audiologists reporting results through the web-based system. This will eliminate much of the human error concerns. Program realizes this will also initially cause additional work, in that we may not receive follow-up screening data for most of the infants that fail the initial screening. Program will be working through this process as we add hospitals and engage our hospital workgroup and Advisory Committee to assist in the development of new policies and procedures to handle this issue.

The staff for the Pennsylvania newborn hearing screening program consists of a Program Manager, Program Administrator, and three Nursing Services Consultants that provide direct patient follow-up. All of these positions are funded by the Title V Maternal and Child Health Block Grant, funding for the program activities, contracts, meeting, travel, etc. are funded by a state appropriation for newborn hearing screening and our current HRSA grant. In July 2008, Governor Edward G. Rendell signed Act 36 implementing the addition of 22 conditions for follow-up for Pennsylvania's bloodspot screening program. There was no funding attached to this legislation. Additionally, creating new positions to handle the additional case load for the bloodspot screening program was impossible due to the Commonwealth's and National current financial situation. The nursing services consultants that provide direct patient follow-up for hearing screening, starting July 1, 2009, will also provide follow-up for one of the new conditions, cystic fibrosis. This additional workload will inevitably affect the number of cases our follow-up nurses will be able to follow for hearing screening as well as the protocols used to locate families and follow infants to diagnosis for hearing loss. Newborn hearing screening staffs are working closely with the bloodspot screening staff to develop protocols that are similar to the hearing screening protocols as well as follow a similar

time line. This will streamline the process of follow-up for cystic fibrosis allowing time for UNHSI cases.

Correct PCP and family contact information is a system wide concern in newborn screening. The national trend to loose families because of incorrect contact information and incorrect PCP contact information also exists in Pennsylvania. This is a system-wide issue affecting both the newborn hearing screening and bloodspot screening systems. As our program has been brought into the implementation of the bloodspot screening program, we have been hearing the same concerns the hearing screening program has been experiencing for years. In many cases the reported family contact information is incorrect and the PCP has no knowledge of the child and is not a patient at their practice. A starting point of this issue is to educate the mothers during the prenatal period and sharing this information with the obstetricians and midwives to encourage mothers to think about screening and the contact information before coming to the hospital to deliver. The Department is currently changing the language in our newborn screening brochure to highlight this issue as well as providing informational sessions to physicians and midwives on this issue and the upcoming changes to the bloodspot screening program. The hospitals are the second line of defense on this issue. The revisions to the newborn hearing screening referral form will help in this area. A section will be added to the form for a second contact for the family. This will be a relative not living with the family. During our NICHQ collaborative activities, our program found that we were able to locate 100% of the 17 cases in the test with the addition of a second family contact. Lastly, we plan to utilize the expertise of our hospital workgroup to develop best practices in this area.

Our last significant challenge is confirmation of enrollment in early intervention services. In Pennsylvania the Departments of Public Welfare and Education serve as the lead agencies for early intervention (EI); however, since 2003, the Bureau of Early Intervention Services, in the Office of Child Development and Early Learning (OCDEL) has administered both the birth-to-three services and those for preschoolers (from three years of age to school entry). Locally, early intervention services for children birth to age three and their families are administered by county EI Coordinators within MH/MR offices. Local school districts, intermediate units and private agencies administer the preschool EI services to children ages three to school age. By combining all services for early childhood education at the state level under one roof, Pennsylvania has been able to achieve many innovative accomplishments, including a joint (birth-to 5) Evaluation Report, and IFSP/IEP forms and a joint EI Management Verification/Monitoring tool. The underlying message and philosophy of such an organizational structure says that children are all more alike than different.

The Department of Health has been working closely with the OCDEL on modifying their parent consent form by adding the Department of Health Newborn Hearing Screening program to the form. This modification was in development for several years and a final draft was presented in early March 2009 to the Department. Once the newborn hearing screening program is able to communicate with EI we'll be able to obtain information on the exact services a child is receiving. The Department occasionally receives information

through our participating audiologists that EI does very little for children with unilateral hearing loss. The newborn hearing screening program would like to know more about this issue to improve services to those children that still need educational assistance. This connection will also provide insight into some of the cases that may have been lost to follow-up in UNHSI and later show up in EI.

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 mandated conditions for testing and beginning July 1, 2009, 28 conditions for follow-up. The Department's UNHSI program began in 1999 as a pilot project in 26 birthing hospitals. The project proved the practicality of implementing UNHSI 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 112 birthing hospitals and a comprehensive UNHSI follow-up, outreach, reporting and EI referral program within the Department.

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

- David Marchetto, MS, CPH. Director, Newborn screening & genetics (15% effort)
- Mary King-Maxey, Program Manager, Newborn Hearing Screening Section (85% effort)
- Arthur Florio, UNHSI Program administrator (100% effort)
- Keith Koppenhaver, RN, UNHSI Nurse Consultant (90% effort)
- Angela Collins, RN, UNHSI Nurse Consultant (90% effort)
- Frank Berkoski, RN, UNHSI Nurse Consultant (90% effort)

The above mentioned nursing services consultants conduct follow-up and tracking activities for newborns referred to the program. In the past, state funds have been utilized to fund a college intern throughout the year to provide assistance and support in follow-up activities, technical support and on-going quality assurance; however, due to budget constraints there is a statewide hiring freeze on all positions including interns.

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 PCP is incorrect, one of the community health nurses will locate the home and do a home visit to encourage the family to get the child a second screening or diagnostic exam. Additionally, they can assist the family in applying for health care

coverage and provide information on where they can get the child screened and connect them with transportation resources if needed.

Part of the provisions of Act 89-2001 is the creation of an 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 UNHSI program. Meetings are held on a quarterly basis in Harrisburg. Current membership includes three physicians, one parent advocate and two audiologists. One of our two audiologists was the late Judy Gravel, PhD; she was the chair of our committee and Director of the Center for Childhood Communications at The Children's Hospital of Philadelphia. Our other audiologist is in private practice in the Wilkes-Barre/Scranton area. One of the physicians is a Pediatric Otolaryngologist at Children's Hospital of Pittsburgh as well as an assistant professor in Otolaryngology and the Director of the Hearing Center. Another one of our physicians is Family Practice staff physician at Frankford Hosptial. This physician is also the parent of a child that is hard–of-hearing. The third physician is a Neonatologist at The Children's Hosptial of Philadelphia. Lastly, our parent advocate has two children with hearing loss. In addition to attending our quarterly meetings, committee members take an active role in the program by participating in workgroups and conference calls with the program's vendors to assist with special projects. A descriptive table listing the committee members is attached. Past committee members are still included in communications about the meetings as well as discussions on program issues. The committee meetings have a large stakeholder presence 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, Office of Deaf and Hard of Hearing to name a few.

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 AAP to provide feedback from the web-based training curriculum and feedback from technical assistance back to the Department to make improvements to program services provided to PCPs. 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. The parent survey provides feedback on the EI system and the newborn screening 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 workshops.

Reviews of IFSPs will be conducted 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 that will be shared with the Department to help shape and improve Guide by Your Side Services.

Organizational information

As previously mentioned, the Department of Health's BFH houses the Newborn Hearing screening program in its Division of Newborn Screening and Genetics. The Department's and Bureau's organizational chart are attached. 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 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 Newborn bloodspot screening program. Each of these programs support the families involved in the newborn hearing screening program.

Act 89-2001 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 who 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. Fortunately, funding was also appropriated with this act and continues currently. The Department is also charged with administering the program, providing technical support to health care facilities and others implementing the screening requirements. 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, if the percentage screened falls below this minimum the Department in consultation with the advisory committee shall 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. Individual referrals for infants that fail the hearing screening are manually linked in the Department's newborn screening data system to their bloodspot screening results. Follow-up contact notes, letters to PCP and parents and a place to enter screening results and diagnostic results are all components of the current data system. Unfortunately, the system is flawed and will open and close cases at will as well as create duplicate cases, making accurate automated counts unreliable. Therefore, most of the data provided from the system is cross referenced with several manual records and

spreadsheets to calculate the program's data that is reported in this application as well as the Centers for Disease Control's annual survey.