

Project Narrative

Introduction

The Pennsylvania Early Hearing Detection and Intervention program (PA EHDI program) is housed at the Pennsylvania Department of Health (Department), in the Bureau of Family Health (BFH), Division of Newborn Screening and Genetics (DNSG). In response to the lack of newborn hearing screening and adequate follow-up, the Universal Newborn Hearing Screening and Intervention Program became law in Pennsylvania in July 2002 through the passage of the Infant Hearing Education, Assessment, Reporting and Referral Act (IHEARR Act). The purpose of the IHEARR 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.

The major provisions of the IHEARR Act include the following:

- Empowers the Department to administer a statewide newborn hearing screening, follow-up and referral program
- Requires hospitals to provide parents of newborns with information on the importance of newborn hearing screening
- Requires hospitals to report newborn hearing screening results and certain other related information to the Department
- Provides an opportunity for all newborns born in Pennsylvania to receive a hearing screening
- Establishes a six-member Infant Hearing Screening Advisory Committee (IHSAC)
- Requires the Department to establish a program to screen out-of-hospital (OOH) births

The purpose of the PA EHDI program's proposed project is enhancing the current EHDI system of care so families with newborns, infants, and young children up to three years of age who are deaf or hard of hearing (D/HH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI). The PA EHDI program will focus on four main methods to achieve project objectives. The focus areas are:

- Leading efforts to engage and coordinate all stakeholders in the EHDI system to meet the program goals
- Engaging, educating, and training health professionals and service providers in the EHDI system
- Strengthening the program's capacity to provide family support and engage families with children who are D/HH as well adults who are D/HH
- Facilitating improved coordination of care and services for families and children who are D/HH

The PA EHDI program will utilize the following objectives to measure progress outcomes:

- Percent of infants that receive a hearing screen by one month of age

- Percent of infants that receive a diagnostic audiological evaluation by three months of age
- Percent of infants identified as D/HH that are enrolled in EI by 6 months of age
- Percent of families with a D/HH child enrolled in the PA Guide By Your Side (GBYS) program by six months of age
- Percent of families with a D/HH child who receive services from the deaf mentor program by nine months of age
- Number of health professionals and service providers receiving training on key aspects of the EHDI program

Needs Assessment

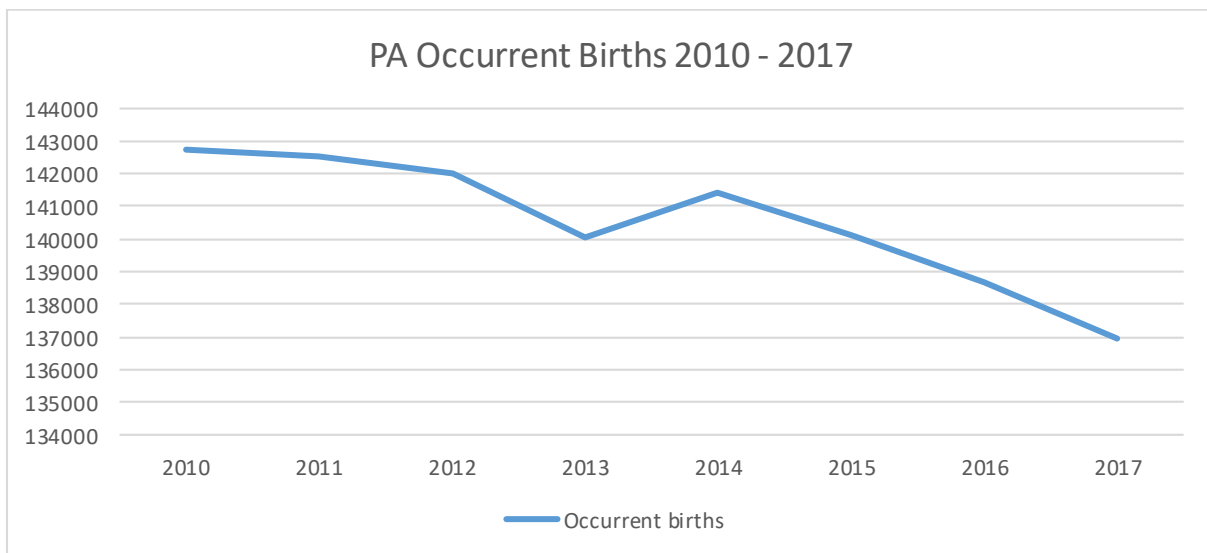
PA's EHDI system is a collaboration across agencies and families with the purpose of ensuring that newborns, infants and young children who are D/HH are identified and get the care they need when they need it. The largest group of stakeholders within the EHDI system are referenced as submitters. Submitters include birthing hospitals, free-standing birthing centers and midwives. Currently, there are 100 birthing hospitals/free-standing birthing centers and 98 midwives performing deliveries in PA. In 2018, the DNSG required individual level reporting, which mandated that submitters report all hearing screening results to the PA EHDI program. The previous requirement was to only report not passed (referred) hearing screening results. The 2018 data is in the process of being cleaned and analyzed, and it will be the first time the program has true baseline data for screening, diagnostic and EI referral and enrollment data. Data provided from 2015 to 2017 is a mixture of aggregate reports from submitters and diagnostic data from newborns with a reported referred screening result.

Data sharing has also been expanded with other stakeholders during the current grant agreement via a data share agreement with the PA EI program and a data match with the Department's birth certificate data which has greatly improved the program's data capacity. In addition, the DNSG has entered into a data share agreement with West Chester University who will be assisting the PA EHDI program in the analysis of program data and will be looking at disparities by race/ethnicity, birth hospital, and geographic location to determine where program efforts should be focused.

In 2017, the DNSG established the Early Hearing Detection and Intervention Advisory Group (EHDI-AG). This group is comprised of stakeholders from across the EHDI system with 25 percent of its members being a D/HH individual or a parent of a D/HH individual. This group was formed in addition to the IHSAC as the advisory committee is limited by law to a six-member committee. However, the DNSG did not want the groups to function independently, therefore, the EHDI-AG meets jointly with the IHSAC. These groups have been instrumental in guiding the program in the development of learning communities and professional development activities; have provided advice on program follow-up activities; and have made recommendations for moving the program forward in the accomplishment of program goals.

The PA EHDI program has had a longstanding partnership with the Tuscarora Intermediate Unit 11 (TIU). TIU has an agreement with Hands and Voices of Pennsylvania to implement the GBYS program in PA. The PA EHDI program has supported this venture by funding TIU to offer family-to-family support to families with children who have been identified as D/HH. In addition to the GBYS program, TIU offers a deaf mentor program which offers D/HH adult consumer-to-family support to families with children who have been identified as D/HH. Identified as a need, the PA EHDI program is exploring options with TIU to improve the data collection and reporting related to GBYS program and deaf mentor program activities and will work with TIU to collect the required data.

PA is the fifth most populous state and is home to over 12.8 million people. The median age of PA residents is 40.8 years old, nearly three years older than the US median age. From 2010-2016, PA’s population grew less than one percent, and the state has continued to see significant declines in the number of occurrent births over the past four years.

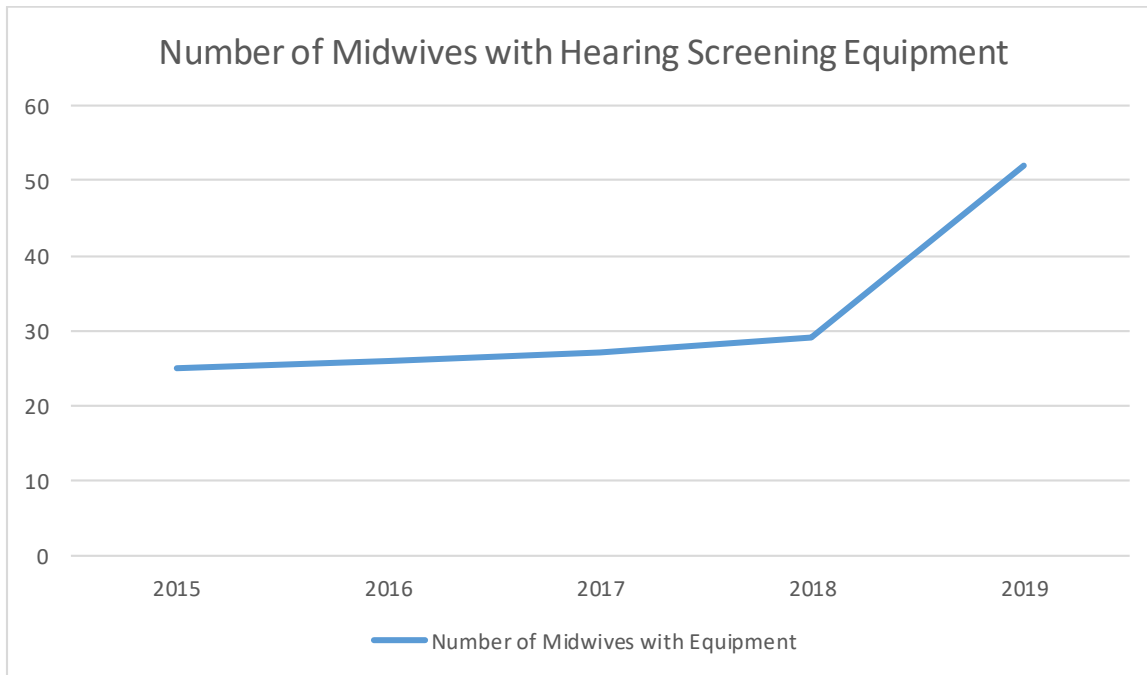


Source: PA Department of Health, Division of Health Informatics, Live Births by Hospital and Method of Delivery, Pennsylvania Occurrences reports from 2010 – 2017.

In 2017, there were 136,950 infants born in PA, with 96.5 percent occurring in hospitals, 1.2 percent occurring in free-standing birthing centers, and 2.3 percent occurring in other settings (ex. clinic/doctor’s office and home births). From 2015-2017, the percentage of newborns receiving a hearing screening has remained steady, with 96.3 percent of newborns being screened in 2015, 95.9 percent in 2016, and 96.3 percent in 2017. However, the percent of newborns receiving a screen by one month of age was slightly below the goal of 95 percent at 93.3 percent in 2015, 93.5 percent in 2016 and 94.5 percent in 2017. During that same time period, the percentage of newborns that were not screened, as they were a home birth, has declined slightly from 2 percent in 2015 to 1.7 percent in 2017.

In order to increase the number of infants screened who were born in a setting other than a hospital or birthing center, the PA EHDI program has continued to provide hearing screening

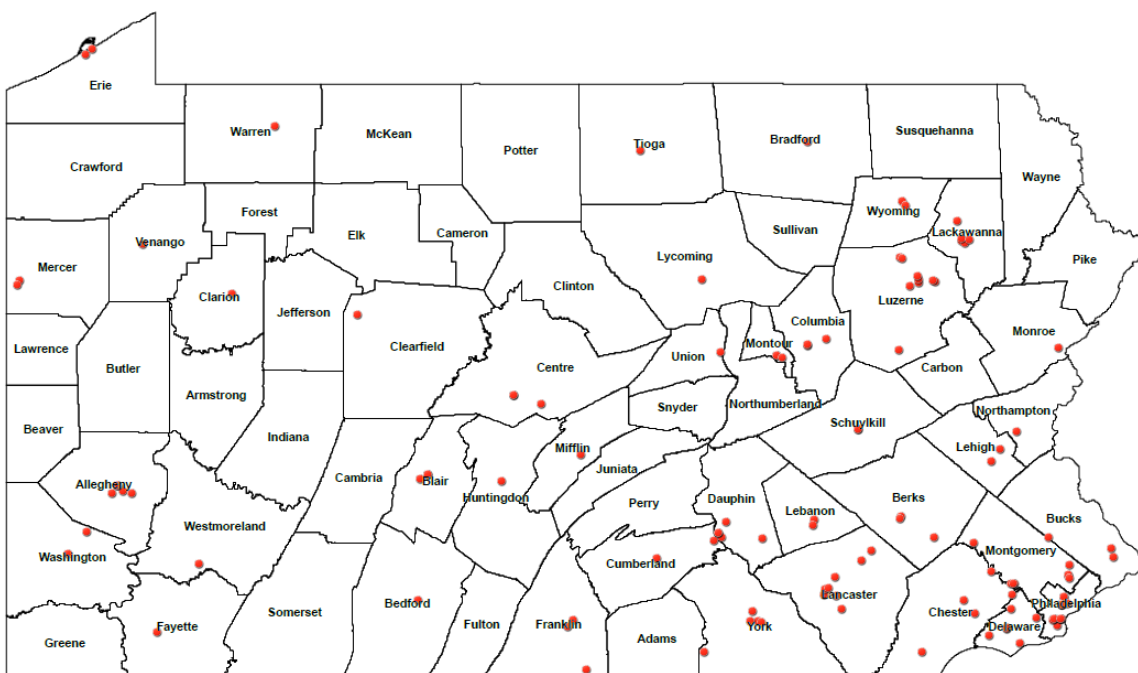
equipment and supplies to midwives willing to conduct hearing screens. The program has purchased additional hearing screening equipment with Title V Maternal and Child Health Services Block Grant (MCHSBG) funding to double the number of midwives with equipment from 2015 to 2019. By the end of 2019, 50 percent of the midwives in the state will have hearing screening equipment, which should improve hearing screening numbers in 2020 and moving forward. In addition, most of the midwives with hearing screening equipment share the equipment with other midwives in their area.



Source: EHDI Program Data

While the PA EHDI program has made significant progress in screening infants, data shows that there needs to be a larger focus on getting infants a diagnostic evaluation by three months of age. In 2017, 58.3 percent of newborn who did not pass their final/most recent hearing screens received a diagnostic evaluation, however, only 39 percent were by three months of age. As the below map shows, there are many counties without an audiologist that can see infants, meaning families in need of an audiologic evaluation, are forced to travel to see an audiologist and often cannot get an appointment before three months of age.

Pennsylvania Audiologists Reporting Diagnostic Results



Source: EHDI Program Data

Of those infants without a documented diagnostic evaluation, most cases were closed as Parent/Family Contacted but Unresponsive, indicating the family was a documented no show for an appointment, or Unable to Contact, indicating the program did not have current/correct contact information for the family. In 2018, the PA EHDI program revised its follow-up process to include sending a no-show letter to parents before closing the case, and once 2018 data is finalized, the program will assess the impact of the no-show letter. Based off those findings, the program will determine what additional steps can be taken to reduce the number of infants not receiving a diagnostic evaluation.

As infants are not getting diagnosed by three months of age, it is reasonable to assume that infants are not getting enrolled into EI by six months of age, and the data support this. In 2017, 71.5 percent of infants with a permanent hearing loss were enrolled in EI, however, only 32.6 percent were enrolled by six months of age.

Other disparities are based on geography, income, insurance, race and ethnicity. PA is an increasingly diverse state comprised of large rural areas and concentrated urban centers which are both evolving economically and socially. PA is anchored by two urban counties, Allegheny in the west and Philadelphia in the east. Urban counties are those with a population density higher than the state population density, while rural counties have a lower density. The delivery of healthcare services is significantly impacted by the distinctive rural and urban characteristics

across the state. While 48 of PA's 67 counties are considered rural, nearly three-quarters of PA's residents live in urban counties. There are 20 counties, all classified as rural, without a hospital/birthing center. Of those 20 counties, six have a midwife based in that county.

The median income in PA varies by county from \$37,100 - \$92,00; with median income for families with children being \$72,878. However, there are stark differences in median income when considering family type. The median income for married families is approximately \$97,300, \$42,500 for male led families and \$26,300 for female led families. In addition to income, health insurance is a key factor in receiving care. In 2017, 5.5 percent of PA's civilian, noninstitutionalized population were uninsured. By gender, 6.4 percent of men were uninsured compared to 4.6 percent of women. While the uninsured rate ranges from 4 to 13.2 percent across counties, the uninsured in PA are primarily working families with an income below 400 percent of the federal poverty level and white.

Following a national trend, PA is becoming more racially and ethnically diverse. From 2010-2016, the minority population increased from 36 percent to 39 percent nationally, and from 21 to 23 percent in PA. Minority residents make up more of the population in urban areas (30 percent) than in rural areas (9 percent). The population identifying as Hispanic increased in PA by 25 percent from 2010-2016, increasing by at least seven percent in every county. From 2000 to 2015, the rural population became more racially diverse, as the non-white or Hispanic rural population increased from five percent of the total population, to nine percent. As of 2017, approximately one in three Pennsylvania children are children of color.

Methodology

The PA EHDI program's goal is ensuring all newborns are screened for hearing loss, that all children with a refer hearing screening result are receiving a timely evaluation and diagnosis, and that all children identified as D/HH are enrolled in EI in a timely manner. The PA EHDI program will utilize the following objectives to measure progress towards this goal:

- Percent of infants that receive a hearing screen by one month of age
- Percent of infants that receive a diagnostic audiological evaluation by three months of age
- Percent of infants identified as D/HH that are enrolled in EI by 6 months of age
- Percent of families with a D/HH child enrolled in the GBYS program by six months of age
- Percent of families with a D/HH child who receive services from a deaf mentor by nine months of age
- Number of health professionals and service providers receiving training on key aspects of the EHDI program

Data for these objectives will come from several sources including, but not limited to: the newborn screening data system, iCMS; the GBYS program; EI; and training events. The newborn screening data system, iCMS, is a secure web-based software application developed and supported by Neometrics™, a division of Natus Medical Incorporated. The PA EHDI program has been using iCMS since July 2016 to capture data on newborns with a referred hearing screening result. Phase II of the system was rolled out in 2017, which allowed submitters to enter hearing screening results directly into the iCMS via manual entry, device upload or HL7 messaging. Effective January 2018, all individual level hearing screening results, including non-screened results, were required to be entered in iCMS. Phase III of the system went live in June 2019, which allows audiologists to directly enter diagnostic information into iCMS. The system also has the ability to capture EI referral and enrollment data, which is entered by the follow-up staff once received from the EI data share. The PA EHDI program is exploring options to add a GBYS and deaf mentor role in iCMS so the guides could directly enter family support activities into iCMS. If that is not feasible, the program will work with the programs to ensure they have a method for collecting and reporting enrollment data for GBYS and deaf mentor activities in order to measure the related objectives. For any trainings that are held, the program will track participation as well as require evaluations from the sessions to have data for the related objective.

The PA EHDI program will focus on four main methods to address the needs and meet the goals, objectives, requirements and expectations of this funding. The focus areas are:

1. Leading efforts to engage and coordinate all stakeholders in the EHDI system to meet the program goals. Within this focus area there are several activities that will be undertaken including:
 - a. Continue to provide a coordinated infrastructure to ensure the program is meeting the 1-3-6 guidelines and work to reduce the number of infants lost to follow-up. The DNSG has six community health nurses (CHNs) that follow-up on all referred hearing screening results and follow these infants until they have a normal hearing screen, are diagnosed with normal hearing, or for those identified as D/HH, until they are enrolled in EI. In addition, the DNSG has a full-time EHDI program administrator, another program administrator that provides support to the EHDI program, and a quality assurance (QA) nurse that assists in quality improvement (QI) activities. These staff work together to attempt to meet the 1-3-6 guidelines and make improvements where the PA EHDI program is not meeting the goals.
 - b. Develop a plan to expand the PA EHDI program infrastructure to include data collection and reporting of hearing screening results for children up to age three by the end of year two of this funding. With iCMS, the program has the capacity to accept hearing screening data from providers that are screening children outside of the newborn period. The PA EHDI program has started conversations with Early Head Start on the reporting of hearing screening data for the screenings they complete on children up to age three. In the first year of the grant, the PA EHDI program will work to train Early Head Start programs on data

reporting and will work on identifying other providers that may be screening children outside the newborn period to have a solid plan in place by the end of the second year of this grant.

- c. Establish and maintain partnerships for referral, training, and information sharing with stakeholder organizations. During the current HRSA grant the PA EHDI program was successful in establishing five learning communities (LC) and at the time of this writing is in the process of establishing a sixth LC. The program will continue the LCs during this four-year funding period. The regional LCs will meet on a quarterly basis to identify barriers to meeting the 1-3-6 guidelines in their geographic area and to identify training needs of health professionals and service providers. These LCs support the education of health professionals and service providers by bringing together a diverse group of EHDI stakeholders to discuss how to improve the 1-3-6 data in their geographic area, identify training needs and provide an avenue for the PA EHDI program to provide training. In addition to the LCs, the program will continue to assess partnerships. By the end of year one of the grant, the PA EHDI program will complete an assessment of current partnerships that are focused on referral, training, and information sharing and will identify key partners who can help address gaps in the EHDI system. This assessment will be revised annually to address new gaps or newly identified key partners.
- d. The PA EHDI program was very successful in establishing an EHDI advisory committee, known as the previously mentioned EHDI-AG, made up of stakeholders from across the EHDI system. This group will continue to meet three times a year, for the duration of this funding, in conjunction with the IHSAC. In the first year of the grant, and throughout the terms of the agreement, the program will review the current membership to ensure 25 percent of members continue to be parents of children who are D/HH or D/HH adults, that members who have not been active are replaced with someone from a similar stakeholder group, and that all key stakeholders are still being represented. Attachment six contains a list of current EHDI-AG members and their organizations.
- e. By the end of year two, the PA EHDI program will have a plan to address diversity and inclusion of the EHDI system to ensure activities are inclusive of and address the needs of the population it serves. Currently, within the BFH, all grant agreements include language requiring the grantee to develop and maintain a plan for addressing health disparities throughout the term of the grant agreement. In addition, the BFH has focused work force development activities on health disparities and inclusion. In addition, with the more robust data for the program and the data share agreement with West Chester, the program is already beginning to look at disparities in screening, diagnostic and EI data. Therefore, the PA EHDI program is poised to have a solid plan completed by the end of the second year of the grant.
- f. The PA EHDI program will continue to implement strategies to monitor and assess program performance towards meeting stated goals and objectives using

continuous QI methods. The DNSG employs a full-time nursing services consultant that serves as the QA nurse. The QA nurse focuses on QA and QI activities throughout the DNSG. The QA nurse will work with PA EHDI program to further develop and revise the newborn hearing screening follow-up processes, evaluate data, identify gaps and barriers, and make recommendations to improve the program. The QA nurse, in conjunction with the EHDI program administrator, will provide technical assistance (TA) to submitters, primary care providers (PCP), and audiologists on reporting requirements, best practice guidelines, timeliness and other topics as needed. During this four-year grant, the program will focus on improving the percentage of infants that receive a diagnostic evaluation by three months of age and the percentage of infants that are enrolled in EI by six months of age. The PA EHDI program will work with the EHDI-AG and the IHSAC on identifying strategies for improvement in these areas.

- g. During the first year of this grant, the PA EHDI program will transition the information on the www.paeearlyhearing.org website to the Department of Health's website. This transition will allow the PA EHDI program to maintain and sustain a website dedicated to the PA EHDI program without paying a contractor to maintain the site. In addition, this move will allow the PA EHDI program to more easily update and ensure that website content is up to date and appropriate for all the various stakeholder populations. Once the transition is complete, the PA EHDI program will advise EHDI stakeholders of the change and will continue to promote the Department's website throughout the four years of this grant.
 - h. The PA EHDI program will develop a sustainability plan for after the period of federal funding ends. There is currently a bill moving through the PA legislature that would implement a newborn screening fee. This fee could potentially provide funds for the PA EHDI program after the federal funding period ends.
2. Engaging, educating, and training health professionals and service providers in the EHDI system. Within this focus area activities include:
 - a. Conducting outreach and education to health professionals and service providers in the EHDI system. The PA EHDI program has developed hearing screening instructions for submitters, PCP instructions on follow-up of hearing screening and diagnostic results, and instructions for audiologists on diagnostic evaluations, which are available on the Department's website. The PA EHDI program will continue to distribute and promote these resources to health professionals. In addition, during the first year of the grant, the PA EHDI program will work with the IHSAC's audiologist sub-committee to develop a training for audiologists. Once developed, this training will be available throughout the federal funding period. Training topics include:
 - 1-3-6 Guidelines
 - Importance of hearing screening up the age of three
 - Benefits of patient/family-centered medical home and family engagement

- Appropriate communication with families for decision making
 - PA EHDI program system information
- b. The PA EHDI program will identify relevant conferences where they can exhibit or present on the PA EHDI program, the importance of meeting the 1-3-6 guidelines, and the importance of communicating evidence-based information to families throughout the diagnostic process.
 - c. The PA EHDI program will utilize funds from this grant for parent scholarships to attend the Great Start conference. This conference addresses service needs and programming for young children (birth to age 5) with deafness/hearing loss; deaf-blindness; blindness and visual impairments; complex needs and traumatic brain injury. The conference focuses on providing current information to increase the skills and knowledge of those living and working with these children. The conference will not only provide education sessions for professionals but will also provide an opportunity for professionals and families to interact and learn from each other.
 - d. TIU will provide an annual training each grant year to EI service coordinators on topics related to the identification, referral and enrollment of newborn and infants who are D/HH in EI.
 - e. The PA EHDI program will continue to collaborate with HRSA LEND recipients, the National Resource Center for Patient/Family Centered Medical home recipient and any relevant future recipients to engage and education health professionals. Currently, the state has two LEND programs and a representative from each program is a member of the EHDI-AG.
3. Strengthening the program's capacity to provide family support and engage families with children who are D/HH as well adults who are D/HH. Activities in this focus area include:
 - a. Engaging families and involving family partners in the development, implementation, and evaluation of the PA EHDI program. As previously stated, the PA EHDI program will continue several activities to engage families. These include continuation of the LCs and the EHDI-AG. In addition, the PA EHDI program plans to utilize funding from this grant to continue an annual family weekend in partnership with the PA Hands and Voices Chapter. This event was started in 2019 and was very successful. The weekend is intended to grow membership for the PA Hands and Voices chapter and to provide an opportunity for families with children who are D/HH to come together to network, learn from each other, and to provide an opportunity for children who are D/HH to interact and spend time with other D/HH children.
 - b. Conducting outreach and education to inform families of the opportunities available to engage with the PA EHDI program. The PA EHDI program, through TIU, will utilize social media and other avenues to advertise to parents of children who are D/HH of the opportunities available to participate in LCs, the EHDI-AG, the Great Start conference, and the family weekend.

- c. Facilitate partnerships among families, health care professionals and service providers to ensure providers understand how to engage families by ensuring that family engagement is an agenda item for the EHDI-AG and LC meetings at a minimum of one meeting per year.
 - d. Utilize funds to continue to support TIU to implement the GBYS program in PA. Since July 2011, TIU has had an agreement with Hands and Voices to operate the PA GBYS program. The PA EHDI program makes direct referrals to the PA GBYS program, sending child specific information on children newly diagnosed as D/HH to TIU every two weeks. The PA GBYS program will then reach out to these families by letter and by telephone, providing information on the PA GBYS program and EI, including information on how to enroll in EI services. The PA GBYS program relies on parent guides to make parent to parent contact on behalf of the program. All parent guides are parents of D/HH children themselves and are trained by TIU. The PA EHDI program will monitor the success of the PA GBYS program through monthly and annual reports. These reports will include the number of families enrolled in the PA GBYS program, the number of families who received family support services, number of referrals made to EI services and number of enrollments into EI services including timeliness measures. The PA EHDI program will provide funds to TIU to pay for parent guides who will conduct outreach to families with children newly diagnosed as D/HH. In addition to the GBYS program, the agreement with TIU requires the continuation of the deaf mentor program. The deaf mentor program was implemented in 2016 and will continue during the terms of this grant funding. Utilizing the same referral method, TIU will provide D/HH adult consumer-to-family support to families with children who have been identified as D/HH. The PA EHDI program will provide funds to TIU to pay for deaf mentors who will conduct outreach to families with children newly diagnosed as D/HH.
 - e. Consulting with the Family Leadership in Language and Learning (FL3 Center) for resources, technical assistance, training, education, quality improvement and evaluation in order to strengthen the PA EHDI program's capacity for family engagement and support.
4. Facilitating improved coordination of care and services for families and children who are D/HH. Activities in this last focus area include:
- a. The PA EHDI program will continue to develop mechanisms for training, referrals, and data sharing between the PA EHDI program and EHDI partners. Data share agreements that were started in the current funding period, include agreements with the PA WIC program to identify new contact information for cases that were closed as unable to contact; the PA EI program for sharing of EI referral and enrollment data; and West Chester University for the analysis of PA EHDI program data. The program will also continue to explore other opportunities for partnership, including a new partnership with Early Head Start for the receipt of hearing screening data on children up to age three.

In addition to the four main focus areas discussed above, the PA EHDI program will participate in the Annual Early Hearing Detection and Intervention meeting. The program will send three staff and will provide support to send one family leader to the meeting each year of the grant. The PA EHDI program will also continue to work with other HRSA funded projects including the FL3 Center, the LEND program and NRC-PFCMH recipients to implement new initiatives as opportunities arise.

The work plan (Attachment 1) provides details on the specific tasks that will be completed to achieve the objectives and to implement the strategies outlined above. The work plan also details the timelines for these tasks and the responsible parties for the individual tasks.

Resolution of Challenges

The PA EHDI program anticipates several challenges in meeting the goal and objectives laid out in the work plan. The first challenge is in increasing the percentage of families enrolled in family-to family support services by six months of age. This is due to the struggles in getting children a diagnostic evaluation by 3 months of age. If a child is not diagnosed in a timely manner, it is difficult to get them enrolled in these supportive services by six months of age. Through the activities outlined in the work plan to improve the timeliness of the diagnostic evaluation, it is anticipated they will help the timeliness of support services.

Another challenge faced in the current funding period, and that is expected to continue, is the provision of D/HH adult-to-family support services. TIU struggled to identify D/HH mentors that could provide un-biased information to families and that were geographically dispersed throughout the state. The program is working with TIU and its EHDI stakeholders to identify potential D/HH mentors and other opportunities for families to interact with the D/HH adults, such as during the family weekend and the Great Start conference.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

The evaluation of the PA EHDI program will include the monitoring of ongoing processes and the progress towards reaching the goals and objectives of the project. Standard research tools for statistical analysis will be used for analysis of the data collected. Evaluation instruments will be reviewed with the IHSAC and the EHDI-AG before any data is collected for evaluation purposes. The evaluation plan for this proposal is designed to be a comprehensive process that will analyze both the implementation of project activities (formative evaluation) and the output of the activities and their effectiveness in meeting project goals (summative evaluation). Formative evaluation strategies will ensure that all project activities are implemented according to the design of the project, are completed according to timelines, and that immediate adjustments can be made to project activities as needed. Summative evaluation strategies are focused on ensuring that project activities are achieving the goals and objectives of the project.

The evaluation plan will allow the project to use both qualitative and quantitative data analysis procedures and allow for flexibility in the development of evaluation instruments.

Examples of formative data inputs:

- Records of project staff meetings including minutes and attendance
- Records of IHSAC and EHDI-AG, including agendas, minutes and attendance
- Records of LC meetings including agendas, discussion notes, and participant attendance
- Documentation of training events including agendas, training materials, demographic information of participants
- Documentation of outreach efforts to partner agencies serving young children and their families
- Documentation of the dissemination of project materials including project reports
- Documentation of contacts of family support and deaf mentor staff

Examples of summative data inputs:

- 1-3-6 data
- Family-to-family support services enrollment data
- D/HH adult-to-family support services enrollment data
- Number of health professional and service providers trained on key aspects of the PA EHDI program
- Pre/post questionnaires to assess the effectiveness of training sessions and their impact on attitudes, knowledge, and behaviors
- Satisfaction surveys for families involved in the family support and deaf mentorship activities
- Satisfaction with EI services by families who have children with hearing loss and who are enrolled in the EI program
- Impact surveys to capture the local changes created by the activities of the LCs, including:
 - Regional JCIH 1-3-6 data
 - Regional enrollment data for the GBYS program and deaf mentor program

The evaluation used to assess performance and progress towards meeting the objectives of this funding will be specific, measurable, attainable, realistic, and time-bound. Baseline data will be established using PA data from the 2017 Centers for Disease Control and Prevention EHDI Hearing Screening and Follow-up Survey or via data collected from year one as a baseline. The goals are as follows:

- By March 2024, increase by one percent from baseline per year, or achieve at least a 95 percent screening rate, whichever is less, the number of infants that completed a newborn hearing screen no later than one month of age
- By March 2024, increase by 10 percent from baseline, or achieve a minimum rate of 85 percent, the number of infants that completed a diagnostic audiological evaluation no later than three months of age

- By March 2024, increase by 15 percent from baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be D/HH that are enrolled in EI services no later than six months of age
- By March 2024, increase by 20 percent from baseline the number of families enrolled in family-to-family support services by no later than six months of age
- By March 2024, increase by 10 percent from baseline the number of families enrolled in D/HH adult-to-family support services by no later than nine months of age
- By March 2024, increase by 10 percent from baseline the number of health professionals and service providers trained on key aspect of the PA EHDI program

With an excellent data system, iCMS, the PA EHDI program can easily collect and report data on these performance measures as part of an annual progress report. Hearing screening and diagnostic evaluation results are required to be entered directly into iCMS via the screener or audiologist. Results and their date are collected. In addition, EI data is currently collected. The PA EHDI program is exploring the most effective method to collect GBYS and deaf mentor data. Utilizing iCMS and the evaluation team as referenced below, the PA EHDI program can accurately and timely report progress in meeting the established performance measures.

The EHDI program administrator will be responsible for the oversight of effective tracking of performance outcomes. To complete this tracking, an evaluation team will be developed. The evaluation team will meet monthly throughout the terms of the funding. Evaluation team members will include:

1. Stacey Gustin, DNSG, Acting Division Director - Ms. Gustin has a Bachelor of Science in Nursing and thirteen years of public health experience, specializing in newborn screening. Ms. Gustin has experience with providing oversight and evaluation of federal grant awards from the Health Resources and Services Administration (HRSA), as she currently serves as the project coordinator of the active EHDI grant.
2. Stacey Gustin, DNSG, Program Manager - Ms. Gustin oversees the administrative aspects of all newborn screening programs, including management of contracts and grants, reporting, program evaluation and quality assurance. Before becoming the manager, Ms. Gustin served five years as a newborn screening follow-up nurse and QA nurse. Experiences as a follow-up nurse include daily interaction with submitters, reviewing best practices, and case management.
3. Joseph Wagner, DNSG, program administrator - Mr. Wagner has ten years of public health experience, specializing in newborn screening and management of grants and contracts. Mr. Wagner oversees and contributes to multiple programs, including the PA EHDI program and the PA Breastfeeding Awareness and Support program.
4. Rebecca Bausinger, DNSG, QA Nurse - Ms. Bausinger has a master's degree in Public Health and four years of nursing experience, specializing in newborn screening. Before focusing on QA, Ms. Bausinger served one year as a newborn screening follow-up nurse. Experiences as a follow-up nurse include daily interaction with submitters, reviewing best practices, and case management.

5. Vacant, DNSG, PA EHDI Program Administrator - This position will devote 100 percent of its time to the PA EHDI program. The EHDI program administrator will coordinate project objectives, collect and analyze data for evaluation and planning, create reports, oversee the EHDI-AG, monitor the TIU grant agreement, and serve as the project officer for this funding opportunity.
6. Anne Gaspich, TIU, GBYS Program Director - Ms. Gaspich has a Bachelor of Science degree in Professional Accountancy from Pennsylvania State University. She brings expertise as a parent of a child who was identified by the EHDI program and has received EI and school-age special education that supports to her work. Ms. Gaspich is responsible for ensuring that the formative evaluation strategies are implemented according to the timelines described in the proposal and that any needed adjustments to project or evaluation activities are made as soon as possible.
7. Mary Anketell, TIU, Data Analytics – Ms. Anketell has been working for TIU since 1993 as a Consultant, Project Coordinator for Evaluation, and Program Manager. In her roles with TIU, Ms. Anketell has developed and implemented evaluation plans for statewide training initiatives that focus on both qualitative and quantitative data methodologies. She is responsible for oversight of the data collection, analysis and reporting of the child outcome indicators as part of Pennsylvania’s Early Intervention Program Annual Performance Report to the Office of Special Education Programs. Ms. Anketell has a master’s degree in speech-language pathology from the University of Connecticut and completed post graduate studies in EI at Kent State University.

Obstacles to the evaluation plan include:

1. Audiologists throughout the state lack knowledge and understanding of the PA EHDI program’s internal and external practices. Many audiologists throughout the state are not aware of the PA EHDI program, including the program’s follow-up program, screening and evaluation standards, resources and reporting requirements. To correct this, the EHDI program developed a document, Instructions for Audiologists on Diagnostic Evaluations, and distributed it to all PA audiologists actively providing hearing screenings and/or evaluations to newborns in the PA EHDI program. Additionally, audiologists received iCMS access and training and went live in the system in the summer of 2019. This allows audiologists access to their patient’s newborn screening record and allows them to enter diagnostic evaluation results directly into the data system. Providing audiologist access to iCMS eliminates the need for the excel reporting workbooks that the EHDI program has previously relied on to retrieve hearing evaluation results.
2. Receiving timely hearing screening results for newborns birthed by midwives remains an obstacle. Originally, 29 midwives in areas with the highest geographic concentrations of OOH births received portable hearing screening machines to help screen newborns. However, the number of midwives and OOH births continues to grow. In 2017, 99 midwives performed approximately 4,800 out-of-hospital births, an increase of 12 percent since 2011. To accommodate the growing number of midwives and OOH births, the PA EHDI program has purchased an additional 30 portable hearing screening

machines. A hearing equipment application was developed and distributed to all midwives in the state. Based on number of births, location, and ability to share equipment, 22 midwives received equipment, training, and hearing screening education during the spring and summer of 2019. The remaining eight pieces of hearing equipment will be distributed during the fall and winter of 2019-2020. Upon receiving equipment, each midwife signs an equipment agreement indicating they: have been trained on the use of the equipment; will use the equipment only for newborn hearing screening; agree to report data to the program; and, agree to share the equipment (if applicable) with nearby midwives.

ORGANIZATIONAL INFORMATION

The mission of the Department is to promote healthy lifestyles, prevent injury and disease, and to assure the safe delivery of quality healthcare for all Commonwealth of Pennsylvania citizens. The specific mission of the DNSG is to eliminate or reduce mortality, morbidity and disabilities by screening and treatment of the disorders included in the Pennsylvania Newborn Screening Panel so as to help affected babies live as long and normal of a life as possible.

As noted in the Introduction, the PA EHDI program is housed at the Department, BFH, DNSG. The Director of the BFH is Tara Trego. She is responsible for overseeing the MCHSBG as well as other initiatives focused on maternal, child, and family health. Ms. Trego has worked in the field of public health for 16 years, specializing in the administration and management of public health programs, including directing short- and long-term projects of multiple federal grants and state funds for statewide health programs. Ms. Trego has extensive knowledge, academic and work experience with program evaluation and has previously served as the principle contributor for a number of federal grants or Cooperative Agreements from the CDC, HRSA, and Housing and Urban Development.

There are four divisions within the BFH. The DNSG is directly responsible for the development and administration of programs that screen newborns for hearing loss, critical congenital heart defects, and 37 conditions identified through dried blood spot screening. The organization chart for the DNSG can be found in Attachment 5. A division director oversees the DNSG, however, this position is currently vacant and is in the process of being filled. Ms. Stacey Gustin, who is the current program manager, is currently serving as the acting division director. The division director is responsible for successful implementation and sustainability of the PA EHDI program.

Under the division director are two program managers, Stacey Gustin and Jordan Shover. Ms. Gustin will serve as the project coordinator for this project. She oversees the administrative aspects of all newborn screening programs, including management of contracts and grants, reporting, program evaluation and quality assurance. Ms. Gustin supervises the EHDI program administrator; a nursing services consultant, identified as the QA nurse in this application; and the breastfeeding program administrator who also provides part-time support to the PA EHDI program. The EHDI program administrator position is currently vacant, however, a candidate has been recommended. It is expected this vacancy will be filled by November 2019. This position devotes 100 percent of its time to the PA EHDI program. Once filled, this position will serve as

the EHDI program administrator for this project. Rebecca Bausinger functions as the QA nurse and devotes approximately 40 percent of her time on quality assurance activities for the PA EHDI program. QA activities include providing TA, visiting hospitals, midwives, hearing screening technicians, audiologists, and other health care workers to review program services against clinical practice standards. Mr. Shover supervises six community health nurses (CHNs) who provide short-term follow-up services for newborns with abnormal newborn screening results. Approximately 40 percent of the CHNs time is devoted to providing follow-up services for newborns with abnormal hearing screening results. Follow-up services include receipt of hearing screening and diagnostic results and case management in the event of a referred screening result. All time dedicated to this project by DNSG staff, will be in-kind as all DNSG positions are funded by the MCHSBG. Job descriptions for key personnel from the DNSG can be found in Attachment 2 and biographical sketches for these individuals can be found in Attachment 3.

The DNSG has a long history of working with EHDI stakeholders across the Commonwealth and plans to continue these collaborations. Please see Attachment 4 for letter of agreement, memoranda of understanding, and other description of proposed/existing contracts. TIU has an agreement with Hands and Voices to operate the PA GBYS program. Through the grant agreement with the PA EHDI program, TIU has successfully operated the PA GBYS program as well as served as the EI technical assistance provider for the PA EHDI program since July 2011. Under this grant agreement, TIU provides training and TA to the state EI programs and serves as a statewide resource for the PA EHDI program in achieving the goal of strengthening the newborn hearing screening system by improving the timeliness of entry of infants and young children into Pennsylvania's EI system. TIU also provides education and outreach to Part C EI providers and others who work with children identified with permanent childhood hearing loss and their families; oversees the existing family/peer support program; designs, distributes and analyze responses to a parent satisfaction surveys; and distributes educational materials and provides information about Pennsylvania's EI program. The makeup of the PA EHDI program and its stakeholders all play a vital role in the program's ability to conduct the program requirements and meet the program expectations.

The PA EHDI program and stakeholders will utilize the workplan, which includes timelines, as a tool to carry out planned activities. As previously mentioned, the evaluation team will meet monthly to discuss progress in meeting the goals and activities of this project. In relation to the fiscal component, the EHDI program administrator is responsible for maintaining and reporting federal funds spent and distributed through the grant. Monthly invoices and backup documentation will be reviewed monthly by the program administrator and approved by the project coordinator before any funds are spent or distributed. All expenses will be tracked through monthly invoices and spenddown sheets maintained by the program administrator and reviewed by the project coordinator.

Through the data share agreement with West Chester University, unique needs of the population served can easily be identified. To provide a response to the needs, the Department provides staff and stakeholders with training and information to support provision of culturally and linguistically competent services and the PA EHDI program undertakes efforts to build these

competencies into programs. For example, in October 2018, through a collaborative effort between the BFH and a grantee, a training titled “Implicit Racial Bias Training” was presented by Jaymie Campbell to the BFH. Mr. Campbell has been working in HIV/AIDS services and sexuality education for ten years and has achieved his Master of Arts in Counseling Psychology, in Community Mental Health. Training attendees included all BFH staff and was offered statewide to other BFH grantees. Additionally, in March 2019, the PA EHDI program and DNSG hosted a midwife collaborative meeting in Lancaster, PA to address the needs of this unique population. Midwives throughout the state were invited to attend and participate in the collaborative. Almost a quarter of all Amish people in North America live in Pennsylvania. The PA EHDI program presented on the importance of screening infants and newborns in a timely manner and provided hearing screening equipment training to a group of midwives who previously applied for hearing screening equipment.

The PA EHDI program plans to address diversity and inclusion in the EHDI system to ensure all activities of this project are inclusive and address the needs of the target population by developing a health disparities plan within the BFH, including the PA EHDI program.

As previously stated, the PA EHDI program will execute a new grant agreement with TIU to assist the PA EHDI program in achieving the objectives established through this funding opportunity. Through the grant agreement, TIU will:

1. Provide family support through parent guides and deaf mentors who provide support to families of infants who are D/HH
2. Provide funding for a family weekend
3. Provide funding for the annual Great Start conference

Key staff for this project from TIU are Anne Gaspich and Mary Anketell. Ms. Gaspich, the GBYS program director, has participated in the ISHAC meetings since 2011. She also participates in the Educational Resources for Children with Hearing Loss Committee (ERCHL), a cross-systems committee focused on the needs of infants through school age with hearing loss. She has presented at the annual PA state Low Incidence Institute for four years and has provided other statewide trainings on the EHDI project. At a national level, Ms. Gaspich presented at the 15th Annual Early Hearing Detection and Intervention Meeting. She has attended the National Early Hearing Detection and Intervention meeting as the Pennsylvania Parent representative in 2013, 2014 and 2015 and received the Pennsylvania Otolaryngology Head and Neck Surgery Award for Distinguished Service. Ms. Gaspich has a Bachelor of Science degree in Professional Accountancy from Pennsylvania State University. She brings her expertise as a parent of a child who was identified by the EDHI program and has received early intervention and school-age special education supports to her work. Mary Anketell, Data Analytics, has been working for TIU since 1993 as a Consultant, Project Coordinator for Evaluation, and Program Manager. In her roles with TIU, she has developed and implemented evaluation plans for statewide training initiatives that focus on both qualitative and quantitative data methodologies. Ms. Anketell has a master’s degree in speech-language pathology from the University of Connecticut and completed post graduate studies in EI at Kent State University.