

## **Project Narrative**

### **Introduction**

The Delaware Division of Public Health and Social Services Family Health Systems, Maternal Child Health Bureau, Newborn Hearing Screening, Early Hearing Detection and Intervention (EHDI) Program, request funding to: reduce the loss to follow-up using continuous quality improvement techniques to achieve measurable improvements in the number of infants who receive appropriate and timely follow-up after a missed or failed hearing screen. In order to fulfill the purpose of this grant the Delaware EHDI program must ensure that infants and young children are not only screened and diagnosed in a timely manner, but they are also provided with access to timely early intervention services.

The activities included in this proposal will improve the quality of life for infants through reduction in loss to follow-up and loss to documentation for those infants missing their birth hearing screening and failing their initial hearing screen. Funds from this project will support the day-to-day operation of the Delaware Newborn Hearing Screening Program. Specifically, the funds will support program staff, including a program director and dedicated follow-up coordinator and the Delaware Hands and Voices, Guide by Your Side program. Together these components seek to ensure that all infants receive an initial birth hearing screening by one month of age, those who do not pass screening are referred to an outpatient audiologist for a follow up hearing screening, and in the event that they fail a second time. They are referred to our sole diagnostic center at A.I. DuPont Hospital for Children's (AIDHC) Audiology Department where they will receive a diagnostic screening. This process will determine if the infant is diagnosed with hearing loss or impairment by three months of age, if indicated, then the infant is referred and enrolled into Early Intervention (EI) services by six months of age.

Delaware's Newborn Hearing Screening Program continues to build on over a decade of success. The Delaware Division of Public Health seeks to support the ongoing improvement of processes. In January of 2018 Delaware's Newborn Hearing Screening Program transitioned from Natus Neometrics to Oz Systems. This transition took place due to out sourcing our Metabolic Screening to Nemours A.I. DuPont Hospital for Children (AIDHC) who contracts with Perkin Elmer. This decision was cost effective for the state metabolic screening program. Because of this transition, we selected Oz Systems through a competitive Request for Proposal (RFP) process and they currently provide our state with the collection of hearing screening data. Delaware is utilizing funding from our Center for Disease Control (CDC) Prevention Grant to evaluate the transition from Natus Neometrics to Oz systems. We are currently in our second year of evaluating the amount of data, which has improved after transitioning to Oz Systems. We are utilizing our initial ESSET score as a baseline (62.5%). We are also utilizing our ESSET target score (85%) to score the Oz System. The ESSET score provides us with a baseline to assess our EHDI Program by identifying the strengths and weaknesses of our program; so that we can continue to enhance our services and meet the 1-3-6 Timeline. Through this evaluation process, we will be able to identify where we need to engage health professionals and service providers in the EHDI System regarding the importance of the 1-3-6 timeline.

## **Criterion 1: Need**

### **Demographics**

Delaware is the second smallest state in the nation with a population of 967,171 people who reside in three counties. According to US 2018 Census estimates, Delaware's population is 64% white, 23.4 % black or African American, 10% Hispanic or Latino, 5.0% Asian, 0.8% American Indian or Alaska Native and 0.8% two or more races. Approximately 21.2% of the state's population consists of children 0-19 years of age. Annually, about 11,000 to 12,000 infants are born at one of the state's six birth hospitals, one Birth Center, or at home.

### **Geography**

Delaware is a small mid-Atlantic state located on the eastern seaboard of the United States. Geographically, the state's area encompasses 1,983 square miles ranking Delaware 49<sup>th</sup> in size among all states. Delaware is bordered by the states of New Jersey, Pennsylvania, and Maryland as well as the Delaware River, Delaware Bay and Atlantic Ocean. Centrally located between 4 major cities, Wilmington, the state's largest urban center is within an hour's drive to Philadelphia, PA and Baltimore, MD and within two hour's drive to New York City and Washington D.C.

Of Delaware's three counties, New Castle County, in the northern third of the state is the largest in population with over 60% of the state's population. Wilmington, the state's largest city is located in New Castle County as are two of the state's birthing hospitals the state's non-hospital The Birth Center and the states lone children's hospital-A.I. DuPont Hospital for Children (AIDHC). Kent County and Sussex County, located in the southern two-thirds of the state are more rural than New Castle County. There are four birthing hospitals in these two counties. The state's Amish population was once served by one mid-wife, primarily within Kent County. The state of midwifery within Delaware is changing dramatically with the passing in 2016 of legislation allowing lay midwives to practice without physician back up. Whereas the Delaware EHDI Program worked with the sole licensed home-birthing midwife previously the program is currently reaching out to each newly licensed lay midwife to ensure and reinforce knowledge of regulations and protocols for hearing screening. While the program welcomes the increase of birthing options for Delaware parents' we anticipate that this population may have some difficulties with meeting screening guidelines. We look forward to working through these challenges with the midwives individually and with the new formed Delaware Midwifery Council. We are currently aware of nine midwives serving families in our state. These midwives deliver between 80 – 100 infants a year.

### **Income and Poverty**

In Delaware in 2010, it is estimated that 15.2% of children, ages 0-17, were living in poverty, with the highest rates among those children ages 0-5 (17%). Children in the rural Kent and Sussex Counties were more likely to live in poverty then children in New Castle County. In 2010 19.6 % of Delaware's children, lived in a household with underemployed parents (where no

parent worked full-time, year round. Over one-quarter (28.3%) of children from single parent households in Delaware live in poverty compared to 6.8% of children living in two-parent households. The median income of two-parent households in Delaware in 2010 was \$85,393 compared to \$28,599 for single-parent households. Of Delaware's children, 35.6% lived in a one-parent household in 2010. In 2011, 68,738 adults and 60,849 children received food assistance through Delaware's Supplemental Nutrition Assistance Program (SNAP) and 2,632 adults and 9,271 children received cash assistance through the Temporary Assistance to Needy Families Program.

### **Health Insurance and Access**

In 2013 87.1% of adults in Delaware and 95.5 % of Delaware's children reported having health insurance coverage. Although the state is relatively small, disparities exist between the state's three counties as well as between rural and urban areas of the state with regard to healthcare access and utilization. A shortage of health care professionals in general, and audiologists in particular, exists in both Kent and Sussex Counties as well as parts of the City of Wilmington. These areas have been federally designated as health professional shortage areas. Although insurance coverage in general is quite high among Delaware's children, the newborn screening program faces obstacles in having rescreening done in a timely manner at several of our outpatient audiology practices where practice policy requires a patient to have a Medicaid card in hand prior to appointment. This can often take a month and can significantly delay follow up and contribute to the lost to follow up after inpatient refer.

### **Birth Facilities and Audiology Facilities**

Delaware's Newborn Screening System consists of six hospitals. Christiana Care, in New Castle County, is the state's largest hospital accounting for 58% of the state's annual births. Kent General Hospital in Kent County is the second largest hospital in terms of birth and accounts for about 15% of the state's annual births. Beebe Hospital, Milford Memorial Hospital, which recently changed their name to Bayhealth Hospital Sussex Campus (BHSC), and Nanticoke Hospital in Sussex County account for most of the remaining births in the state. In New Castle County the Neonatal Intensive Care Units (NICU) are located at Christiana Care and the single children's hospital in the state, AI DuPont Hospital for Children. A single level II NICU located in Kent General Hospital serves the southern two counties. The state does have one dedicated birth center known as The Birth Center in Wilmington, Delaware with over 200 births per year occurring at that facility. The state also has a sizeable Amish Community in Kent County that accounts for most of the home births in the state (n<100, annually) and was once served by a single midwife. The state of midwifery within Delaware is changing dramatically with the passing in 2016 of legislation allowing lay midwives to practice without physician back up. Whereas the Delaware EHDI Program worked with the sole licensed home-birthing midwife previously the program is currently reaching out to each newly licensed lay midwife to ensure knowledge of regulations and protocols for screening. While the program welcomes the increase of birthing options for Delaware parents' we anticipate that this population may have some difficulties with meeting birth hearing screening guidelines. We look forward to working through

these challenges with the midwives individually and with the new formed Delaware Midwifery Council. The EHDI Program is aware of nine midwives practicing in the state of Delaware.

Each of the birth facilities in Delaware performs hearing screens on all births. All babies who refer from the birth facilities must be rescreened at an outpatient audiology practice. In Delaware there are currently eight audiology practices that will perform outpatient screenings on newborns. There is two audiologist located in New Castle County and one in Kent County. These audiologist are able to perform diagnostic testing including unsedated ABRs. Sedated ABRs are only available at the AI DuPont Children's Hospital outpatient audiology facility in New Castle County. The lack of sedated diagnostic examination facilities in the southern two counties is a known barrier to patients receiving timely diagnosis.

### **Statutes and Regulations**

Delaware Code Annotated Title 16 §804A., adopted July 2005, requires that newborn hearing screens be conducted prior to hospital discharge for all newborns. As a condition of its licensure, each hospital must establish a Universal Newborn Hearing Screening (UNHS) program. Each UNHS program will:(1) Provide a hearing screening test for every newborn born in the hospital, for identification of hearing loss, regardless of whether or not the newborn has known risk factors suggesting hearing loss.(2) Develop screening protocols and select screening method or methods designed to detect newborns and infants with a significant hearing loss.(3) Provide for appropriate training and monitoring of the performance of individuals responsible for performing hearing screening tests. (4) Perform the hearing testing prior to the newborn's discharge; if the newborn is expected to remain in the hospital for a prolonged period, testing shall be performed prior to the date on which the child attains the age of 3 months. (5) Develop and implement procedures for documenting the results of all hearing screening tests.(6) Inform the newborn's or infant's parents and primary care physician, if one is designated, of the results of the hearing screening test, or if the newborn or infant was not successfully tested. (7) Collect performance data specified by the Division of Public Health.

In August 2012 legislation was passed and signed into law that impacted the Newborn Hearing Screening Program. House Bill 384 amended our current Universal Newborn and Infant Hearing Screening, Tracking and Intervention regulations. The new law mandates reporting by both hospitals and audiologists to the Newborn Hearing Screening Program within 10 days of testing; the direct referral of any infant with a diagnosed hearing loss to Part C for evaluation of eligibility for services

### **Data Management**

The hearing data infrastructure for Delaware's EHDI Program transitioned from Natus Neometrics to Oz Systems on January 1, 2018. The Newborn Screening Early Hearing Detection and Intervention (EHDI) Program went through this transition of out sourcing our metabolic screening to AI DuPont Hospital for Children (AIDHC) who manages our metabolic screening data through a metabolic screening lab called Perkin Elmer. Due to this process, the Newborn Screening EHDI Program had to select another provider to continue the collection of

our Hearing Data. Through a Request for Proposal (RFP) process, the EHDI Program contracted with OZ Systems because their data collection methodology aligned with the reporting requirements of the Center for Disease Control (CDC) and Prevention. In addition, our largest birthing facility in Delaware, which is Christiana Care Hospital Services (CCHS) was actively using OZ Systems prior to the transitioning of the metabolic screening. Therefore, nothing would need to change for the largest birthing facility in Delaware because they were actively using the system prior to the transition. The Delaware EHDI Program utilizes our EVRS Vital Statistics to match infants born in Delaware so that we can verify that all infants born in Delaware who receive a birth certificate receive their initial birth hearing screening. We also are able to look in the Perkin Elmer data system and research the infant’s bloodspot card to verify if a manual entry of the infant’s hearing screening is documented by the nurse, on the bloodspot card. For Outpatient audiologist, they fax or email within 10 days of exam to our office the hearing screening results of infants that required a follow up outpatient hearing screening due to a failed birth hearing screening. In the event that the infant fails the outpatient hearing screening, they are referred to our lone children’s diagnostic center-AI DuPont Hospital for Children (AIDHC) to receive a Diagnostic Evaluation. The Oz Systems is in the first year of transitioning into the Oz Systems. Our birth facilities, Birth Center and diagnostic center-AIDHC are all on board with the Oz Systems. Through ongoing technical support from the Oz Systems Team and Delaware’s EHDI Program team the transition has been a positive transition. The Oz Systems is actively working on the three phase (eSP, NANI, and Telepathy) process to retrieve hearing screening data from each of the birth facilities devices. Oz requires their proprietary data format directly from the hearing devices and HL7 is currently not an option at this time. The new Oz Systems electronic reporting of the inpatient hearing screening data will reduce the error rate encountered by both hospital staff writing results on the bloodspot cards and public health data entry personnel entering the data into the Case Management System. Electronic reporting of inpatient screening results will also reduce the time to initial follow up from the newborn screening program with the primary care physician. With electronic results entering the Oz Systems in real-time it is anticipated that the primary care physician will be notified within 1 week of life, often before the infant’s first visit to the practice with a follow up letter faxed to the primary care physician and a letter mailed to the parent.

Below is a description of the three phases of Delaware’s hearing screening data management system.

<b>Delaware’s OZ Systems Description of Data Management which will align with the CDC’s Goals for EHDI-IS</b>	<b>eSP</b>	<b>Telepathy EHDI</b>	<b>OZ NANI</b>
1. Document unduplicated, individually identifiable data on the delivery of newborn hearing screening services for all infants born in the jurisdiction.	<b>X</b>	<b>X</b>	<b>X</b>
2. Support tracking and documentation of the delivery of follow-up services for every infant/child who did not receive, complete or pass the newborn hearing screening.	<b>X</b>	<b>X</b>	<b>X</b>
3. Document all cases of hearing loss, including congenital, late-onset, progressive, and acquired cases for infants/children <3 years old.	<b>X</b>		

4. Document the enrollment status, delivery and outcome of early intervention services for infants and children <3 years old with hearing loss.	<b>X</b>		
5. Maintain data quality (accurate, complete, timely data) of individual newborn hearing screening, follow-up screening and diagnosis, early intervention and demographic information in the EHDI-IS.	<b>X</b>	<b>X</b>	<b>X</b>
6. Preserve the integrity, security, availability and privacy of all personally-identifiable health and demographic data in the EHDI-IS.	<b>X</b>		<b>X</b>
7. Enable evaluation and data analysis activities.	<b>X</b>	<b>X</b>	<b>X</b>
8. Support dissemination of EHDI information to authorized stakeholders.	<b>X</b>		

**Delaware CDC Newborn Hearing Data**

Delaware has seen progress over the last three years in obtaining newborn hearing data and meeting the 1-3-6 Timeline recommended by the Center for Disease control (CDC) and Prevention. The progress that we have seen is the direct result of the support our state has received from the Center for Disease Control (CDC) and Prevention federal project officer, EHDI Advisory Board and EHDI Quality Improvement Sub-Committee. The partnership the EHDI Program has with Part C Early Intervention (EI) Services known as Child Development Watch (CDW) and Part B 619 Department of Education Early Childhood, Birth Facilities, Diagnostic Audiology Department at AI DuPont Hospital for Children (AIDHC), and Hands and Voices Guide By Your Side parent lead organization. Delaware has showed significant improvement on our Loss to Follow Up (LTFU) Rate. Below is a descriptive timeline capturing Yr. 2015 through Yr. 2017, which demonstrates the following: LTFU Rate, number of diagnostic exams, and the number of infants diagnosed with hearing loss. Also, the number of infants that were diagnosed, by 3 months of age and those that were diagnosed after 3 months of age.

**Based on 11,478 occurrent births in Yr. 2015**

LTFU Rate .0014% (16 infants) with 56.3% (9 infants) of that being parents we were unable to contact and 43.8% (7 infants) we succeeded in contacting but families were unresponsive.

**Diagnostic:** Of the 11,478 occurrent births in 2015 the newborn screening program cannot account for 16 infants hearing status. The state can document 49 diagnostic exams occurred in 2015, diagnosing 25 infants with Hearing Loss.

**1-3-6 Timeline**

Infants Diagnosed w/permanent hearing loss by 3 months of age 11

Infants Diagnosed with Permanent hearing loss: After 3 months of Age but before 6 Months of Age 14.

**Based on 11,415 occurrent births in Yr. 2016**

LTFU Rate 27.2% (31 infants) with 0% (0 infants) of that being parents we were unable to contact and 5.2% (16 infants) we succeeded in contacting but families declined services.

**Diagnostic:** Of the 11,415 occurrent births in 2016 the newborn screening program cannot account for 0 infants hearing status. The state can document 43 diagnostic exams occurred in 2016, diagnosing 17 infants with Hearing Loss.

**1-3-6 Timeline**

Infants Diagnosed w/permanent hearing loss by 3 months of age 0

Infants Diagnosed with Permanent hearing loss: After 3 months but before 6 months of Age 17

**Based on 11,265 occurrent births in Yr. 2017**

LTFU Rate 0% (0 infants) with 0% (0 infants) of that being parents we were unable to contact and 004.4% (5 infants) we succeeded in contacting but families declined Services.

**Diagnostic:** Of the 11,265 occurrent births in 2017 the newborn screening program cannot account for 298 infants hearing status. The state can document 48 diagnostic exams occurred in 2017, diagnosing 12 infants with Hearing Loss. (We had 271 babies move out of jurisdiction and we had 22 infants die)

**1-3-6 Timeline**

Infants Diagnosed w/permanent hearing loss by 3 months of age 9

Infants Diagnosed with Permanent hearing loss: After 6 months of Age 3

**Delaware CDC Newborn Hearing Evaluation Process**

The Delaware Newborn Hearing Screening Data is in the second year of transitioning from Natus Neometrics to Oz Systems. We transitioned from our Newborn Screening Program collecting metabolic and hearing data through our Natus Neometrics vendor to Oz Systems collecting only hearing screening data. With the technical support of our Center for Disease Control (CDC) and Prevention Federal Project Officer, Delaware focused on evaluating the effectiveness, completeness, uniqueness and timeliness of the transition. In year one (FY 2018) we focused on the effectiveness of this transition. Through the evaluation we compared Natus Neometrics and Oz Systems effectiveness of hearing data collection. We counted the number of data collected in the Natus Neometrics Legacy (old system) and the Oz Systems (new system). We used our initial ESSET Score as a baseline 62.5% and we used ESSET to score the Oz Systems (target score 85%). In year two (FY 2019) we focused on the completeness of the hearing data. We found that the EHDI-IS Oz Systems featured complete data on 97.8 percent of infants born within the timeframe (i.e., 10641 live births). Our findings were that when we compared the Natus Neometrics Legacy data to the new Oz Systems the diagnostic data was 85% complete in comparison to Natus Neometrics Legacy data. We also found that the external completeness of external data sets with other sources of information we had 85% complete data or higher in tracking Early Intervention data. In comparing the two systems, we found that the uniqueness of diagnostic data, showed that the percentage of duplications of records in all diagnostic data fields resulted in no duplicity of records or if there was it was less than 5%. In addition, the extent of unique intervention data found that the percentage of duplications of records in all Early Intervention data fields found that there were no duplicity of records.

**Our most recent key findings:** The “3” in the “1-3-6 EHDI Plan” states that “all infants who do not pass the initial hearing screening and the subsequent rescreening should have appropriate audiological and medical evaluations to confirm the presence of hearing loss at no later than 3 months of age.” The Table below provides the number of infants that reportedly did not pass

*both* the birth screening and outpatient screening (“Did Not Pass”), and therefore, should have had an audiological assessment reported within 90 days of birth (“Audiological Assessment”). The corresponding percentages are listed in the table.

Table Below: Number of Infants That Did Not Pass Birth Screening and Outpatient Outcomes and Had Audiological Assessment Within 90 Days of Birth.

Month	Did Not Pass (Both Birth Screening Outcome and Outpatient Outcome)	Audiological Assessment Reported Within 90 Days of Birth	Percent
Jul-18	9	9	100.0%
Aug-18	9	9	100.0%
Sep-18	16	16	100.0%
Oct-18	7	7	100.0%
Nov-18	6	6	100.0%
Dec-18	7	6	85.7%
Jan-19	7	7	100.0%
Feb-19	9	8	88.9%
Mar-19	12	10	83.3%
Apr-19	4	4	100.0%
May-19	5	4	80.0%
Jun-19	14	14	100.0%
FY2019	105	100	95.2%

As evidenced by this table 95.2 percent of infants in FY 2019 had a diagnosis completed by 3 months of age.

Timeliness in documentation of diagnostic data is found to be overall very timely. Of the 10,406 infants reportedly screened, 1,235 (11.9 percent) had a difference that was one day or greater between the first diagnosis date and the date in which information was recorded in the Oz Systems. Of these, the overwhelming majority (944 out of 1,235 or 76.4 percent) had a documentation time of 1 to 7 days between the first diagnosis date and the date in which information was recorded and 1,152 (93.3 percent) had a documentation time of 1 to 30 days between the first diagnosis date and the date in which information was recorded. The average

number of days between first diagnosis and information being recorded in EHDI-IS during the evaluation period is approximately 2 days. Overall, we have found that the Accuracy of the EHDI-IS diagnostic data for Delaware has shown to have no notable discrepancies, errors, and/or incorrect values identified in the data set, and therefore it is held that the data sets contained accurate diagnostic data. Some items that were noteworthy during the evaluation process of our hearing data system was 1. Not all of the infants had a Medical Number Reported. This was not a pressing issue; however, this field was used to determine duplicate entries. The use of the infant's name were then used to identify any outstanding duplicate entries. 2. Race/ethnicity and zip code were not documented for a large number of infants in our Oz Systems.

### **Screening**

Currently there are 6 birthing hospitals and one stand lone Birth Center that conduct birth hearing screenings. Our lone diagnostic center – AI DuPont Hospital for Children (AIDHC) Audiology Department does all the diagnostic evaluations in the state of Delaware. The EHDI Advisory Board recommends that all infants receive an automated ABR (aABR) as the primary screen prior to discharge. However, The Birth Center and the Midwives serving infants in our state have not adopted the recommendation.

### **Strengths:**

- All facilities are conducting hearing screenings, utilizing the Oz Systems and continuing the partnership established with Public Health
- Our largest facility, Christiana Care with 58% of the births in the state has an outpatient audiology department on campus and successfully schedules all infants with an inpatient referral prior to their discharge.
- All facilities submit results of hearing screenings within 10 days of test.
- The Delaware Newborn Hearing Screening Program through its Oz Systems generates and sends letters to both parents and PCPs upon infants' discharge with a failed or missed hearing screen.
- Delaware is successful at rescreening the majority of infants leaving the hospital without a passing hearing screen
- An established system of reporting both outpatient screens and diagnostic exams exists
- An established Governor Appointed Early Hearing Detection and Intervention (EHDI) Advisory Board with members who are appointed to the board based on their expertise and affiliation with the population.
- An EHDI Quality Assurance Sub-Committee that extends recommendation and support to the EHDI Program within Public Health.
- The EHDI Advisory Board is Chaired by our Chapter Champion Dr. Carlos Duran who serves patients at the largest birthing facility in our state, Christiana Care Hospital Services (CCHS).

- Support from the Delaware Statewide Programs for the Deaf, Hard of Hearing & Deaf-Blind mentorship program.

**Opportunities for Improvement and Barriers:**

- Have all birth facilities schedule outpatient follow up screening prior to hospital discharge.
- Work with all hospital to implement the electronic transfer of newborn screening results daily to Delaware Public Health.
- Establish a regular, timely report back to each birth facility to inform them of their referral rates, data completion, loss to follow-up rates and time to diagnosis.
- Work with the Midwifery Council to increase reporting and decrease referral rates.
- Delaware can better utilize our parent lead organization Hands and Voices Guide By Your Side guides to engage families and provide family to family support.
- Also utilize our parent lead organization Hands and Voices Guide By Your Side to educate pediatricians on the 1-3-6 Timeline.
- Encourage our parent lead organization to work in partnership with Delaware Statewide Programs for the Deaf, Hard of Hearing and Deaf-Blind mentorship program that they currently have in place for the families they serve.
- Encourage our parent lead organization to serve as a resource for Early Intervention Care Coordinators serving families of infants who are Deaf/Hard of Hearing (D/HH).
- Delaware does not have a diagnostic facility in our southern counties (Kent and Sussex County). This barrier causes our LTFU rate to increase and late on-set of diagnosis when the child starts Head Start or Kindergarten. Currently our state has only one diagnostic center located in New Castle County. The lone children's Hospital –AI DuPont Hospital for Children (AIDHC) does not have a diagnostic facility in Kent or Sussex County. Families have to travel one hour to reach the diagnostic center if they reside in Kent County and two hours if they reside in Sussex County.

**Addressing Barriers:**

- The EHDI Coordinator will explore with all birth facilities schedule outpatient follow up screening prior to hospital discharge.
- The EHDI Coordinator will work with all hospital to implement the electronic transfer of newborn screening results daily to Delaware Public Health.
- The EHDI Coordinator will establish a regular, timely report back to each birth facility to inform them of their referral rates, data completion, loss to follow-up rates and time to diagnosis.
- The EHDI Coordinator and the EHDI Advisory Board will work with the midwives to increase reporting and decrease referral rates.

- The EHDI Coordinator, EHDI Advisory Board and the Delaware Statewide Programs for the Deaf, Hard of Hearing 7 Deaf-Blind will work with Hands and Voices Guide (H&V) Guide By Your Side to better utilize their services and extend support to them on engaging families and provide family- to - family support.
- The EHDI Coordinator will establish a contract with a workplan for Hands and Voices Guide By Your Side to educate pediatricians on the 1-3-6 Timeline.
- The EHDI Coordinator will include in a contract established with Hands and Voices Guide By Your Side to work in partnership with Delaware Statewide Programs for the Deaf, Hard of Hearing and Deaf-Blind established mentorship program that they currently have in place for the families of infants and children who are Deaf/Hard of Hearing (D/HH).
- Encourage our parent lead organization to serve as a resource for Early Intervention Care Coordinators serving families of infants who are Deaf/Hard of Hearing (D/HH).
- The EHDI Coordinator will discuss with AIDHC Administrators an alternative option to implement a diagnostic clinic to serve southern counties (Kent and Sussex County) twice a month. Because, this barrier causes our LTFU rate to increase and late on-set of diagnosis when the child starts Head Start or Kindergarten. Currently our state has only one diagnostic center located in New Castle County. The lone children's Hospital –AI DuPont Hospital for Children (AIDHC) does not have a diagnostic facility in Kent or Sussex County. Families have to travel one hour to reach the diagnostic center if they reside in Kent County and two hours if they reside in Sussex County.

## **Criterion 2: Methodology**

A methodological approach that incorporates collaborative partnerships and best practices while utilizing national expertise will guide the establishment and achievement of project aims. The use of quality improvement methodology will be considered for each aim as the EHDI program strives to achieve its mission of identification of all hearing loss in infants so that intervention is made available to facilitate age appropriate development of language and social skills for all Delawareans.

The Delaware EHDI Program has significant resources available to it in utilizing quality improvement methodology. The Delaware Division of Public Health implements continuous quality improvement (CQI) as an essential component. The Division of Public Health has committed to a process of changing the culture of the organization to one in which the quality improvement process is reflected in all Division goals and outcomes.

With the accumulated knowledge of Quality Improvement practices and the utilization of the Plan Do Study Act (PDSA), Delaware's EHDI Program will meet the following goals:

### **Year 1:**

- Ensure 1-3-6 recommendations are met
- Reduce loss to follow-up and loss to documentation
- Enhance our partnerships for information sharing, referral, and training
  - By the end of project Year 1 conduct an assessment of partnerships
- The EHDI Program in partnership with Title V will assesses and addresses coordination across early childhood programs in an effort to improve services such as IDEA Part C, Home Visiting, and Head Start Programs.

**By the End of Year 2:**

- Support hearing screening for children up to age 3, including data collection and reporting
- Include other stakeholders needed in the plan (Title V-CYSHCN Director, Head Start, Part C, Part B 619 Department of Education, EHDI Advisory Board, Birth Facilities, Hands and Voices/Guide By Your Side-Parent Lead Organization, Delaware Statewide Programs for the Deaf, Hard of Hearing and Deaf-Blind, and Midwives
- Develop a plan to address diversity and inclusion with the support of our EHDI Advisory Board and our EHDI Quality Improvement Sub-Committee (The EHDI Board meets 6 times within a calendar year and the Sub-Committee meets on alternating months from the EHDI Advisory Board)
- Enhance our EHDI Quality Improvement Sub-Committee, which is established as part of the Governor Appointed Advisory Board.

**By the end of Year 3, the EHDI Program will demonstrate:**

- Evidence of Improvement in the following
  - Communication
  - Training referrals
  - Data Sharing

**Throughout the 4 years of this project, Delaware will implement a strategy to monitor and assess program performance on the following:**

1. Partnerships across Title V and other early childhood programs
2. Family engagement and family support
3. Enhance access and improve our existing website to include:
  - accessible
  - culturally appropriate
  - offer accurate, comprehensive and evidence-based information
4. Develop a plan of sustainability for when the funding ends.
  - With the guidance of the EHDI Advisory Board and the EHDI Quality Improvement Sub-Committee

5. Engage Educate and train health professionals and service providers on the EHDI System on topics:
  - Importance of meeting 1-3-6 recommendations
  - Need for continual screening, diagnosis, and intervention up to age 3
  - Through Family-To-Family Support provide current and accurate information to families, including decisions about the full range of assistive technologies and communication modalities
  - Outreach to families and practitioners will include social media and quarterly site visits.
6. The Delaware EHDI Program will contract with a parent lead organization to implement family engagement and early childhood coordination by extending the opportunity to get involved throughout all aspects of the EHDI Program. This will be accomplished by the following:
  - The EHDI Program will contract with Hands and Voices (H&V) Guide By Your Side to implement family engagement and support. They will receive 25% of funding for this activity.
  - H&V will partner with AIDHC to establish rapport to receive referrals with consents from their diagnostic department to provide Family –To - Family Support.
  - H&V will do outreach to Head Start Program making them aware of Family –To-Family Support.
  - H&V will reach out to families through various communication avenues such as emails and social media.

**Expectations:**

The Delaware EHDI Coordinator will allocate within the budget for the duration of this 4 Year project for one to two EHDI Staff (or one can be from Part C) to attend the Annual EHDI Meeting. The EHDI Coordinator will coordinate with the parent lead organization to send one family leader from their Hands and Voices Guide By Your Side Organization.

The EHDI Coordinator and Hands and Voices Guide By Your Side will work together to utilize the resources available through the federal EHDI-partners such as the Family Leadership in Language and Learning (FL3). The FL3 will provide support to our parent lead organization through technical support with resources to enhance Delaware’s EHDI System. Also, the EHDI Coordinator will utilize the Leadership Education in Neurodevelopmental and related Disabilities (LEND) Pediatric Audiology data as a resource to support and strengthen the focus in Delaware on screening, treatment, and follow up in infants and young children who are Deaf or Hard of Hearing and who have autism spectrum disorder (ASD) and /or other related neurodevelopmental disabilities. The EHDI Coordinator will share resources on training opportunities offered by LEND with our listserv, which includes Pediatric Audiologist.

**WORK PLAN:**

The Work Plan will be implemented utilizing the Plan Do Study Act (PDSA) Cycle. The work plan will be descriptive in the process that the Delaware EHDI Program will reach our project goals and objectives over the 4 Year timeline of this project. The timeline for activities will include the individual responsible for completing the activity and benchmarks reached during the project period. The EHDI Coordinator, EHDI Advisory Board and the parent lead organization - Hands and Voices Guide By Your Side will be instrumental in completing the objectives of the goals outlined in the work plan. All of the stakeholders that serve on the EHDI Advisory Board, Hands and Voices Guide By Your Side, Mentors from the Delaware Statewide Programs for the Deaf, Hard of Hearing and Deaf-Blind will all contribute to the planning, designing and implementation of the activities. Both the EHDI Advisory Board and the Statewide Programs for the Deaf, Hard of Hearing and Deaf-Blind have extended letters of support, which shows their commitment to this 4 Year project. (The full work plan can be obtain in Attachment #1.)

**Criterion 3: Evaluative Measures**

The primary purpose of evaluation is to measure to what extent the program goals, strategies and activities were met. Through the four years of the project proposed, the Delaware EHDI Coordinator will meet on a bimonthly basis with the EHDI Board Quality Improvement Subcommittee. We will review results of small tests of change, and spread the changes where effective, revise tests where they are found to be in effective, and identify new areas of need to address though the process of continuous quality improvement. Specifically the team will look to see if the activities have resulted in a reduction of the number of infants lost to follow-up at each stage of the program from inpatient screening to enrollment in Early Intervention. We will use the SMART framework to measure the performance and progress made in meeting our objectives outlined in our purpose and program description of this application. We will evaluate our EHDI System of care and access the specificity, measurability, attainability, if it is realistic and timeliness of our program by the evidence of the data collected in our Oz Systems and ongoing assessment and evaluation with the EHDI QI Sub-committee. We will also utilize the Center for Disease Control (CDC) and Prevention EHDI-Information System (IS) IS data for tracking, surveillance and program improvement. Hearing Screening and Follow-up Survey (HSFS) data as well. Both data resources will allow us to review progress, track where we have met benchmarks and where we can enhance our EHDI Program.

Delaware will impact our EHDI System of Care through the implementation of the SMART framework. Below is a description of each step.

Specific: Data will be collected through the Newborn Screening Natus Database and analyzed on an ongoing basis.

Measurable: All hearing screening records are matched on a weekly basis with our birth certificate records and monthly with our infant mortality report from Vital Records.

Attainable: Annually the Delaware EHDI Program will submit data required by the CDC Hearing Screening and Follow-up Survey.

The EHDI Coordinator and Follow-up Coordinator will monitor the following measures which are presented to the EHDI Board on a quarterly basis (every other meeting):

- Number of infants screened
- Number of infants who Passed hearing screen
- Number of infants who missed screen, excluding those who died or whose parents refused
- Number of infants Lost to Follow-up including those who transferred out of state and whose parents are unresponsive.
- Number of infants who referred on screen excluding those that died, whose parents declined follow-up, moved out of state
- Number of infants with a completed diagnosis
- Number of infants lost to follow-up at diagnosis
- Number of infants with a confirmed hearing loss
- Number of infants referred to Part C/Early Intervention
- Number of infants receiving Part C/Early intervention services
- Number of infants that were referred to Part C/Early Intervention but are not enrolled
- Number of infants Lost to Follow-up.

Realistic: The EHDI Coordinator and Director of CYSHCN has access of all systems and is able to obtain the data from the Oz Systems. Technical Support is available from the Oz Systems Team in obtaining the information needed to assess and measure progress made in the EHDI System of Care. Delaware's lone diagnostic center AI DuPont Hospital for Children inputs hearing results and diagnostic results into our Oz Systems. As a back up they fax over the diagnostic hearing results as well. This is extremely beneficial to our EHDI System of care because we are able to make the referrals to Early Intervention as soon as the infant is diagnosed.

Time-bound: The Oz Systems allows us to receive hearing screening data in real time. Although we are still transitioning through the three phases of the Oz Systems we are able to receive data rapidly compared to our old data systems called Natus/Neometrics.

#### **Criterion 4: Impact**

The extent to which the four year project will impact Delaware's EHDI Program will be substantial. It will increase and continue to grow the knowledge of the EHDI System in our state. Stakeholders and professionals practicing in the medical field and throughout Title V will see the significance of meeting the recommended 1-3-6 Timeline and the long-term effects of

language, literacy, and social-emotional development; when an infant receives early intervention services by 6 months of age. The EHDI Program will be able to enhance our relationships with the Midwifery Council through educating them of the importance of meeting the 1-3-6 Timeline that is recommended by the CDC. This project will enhance the Family-to-Family support for Deaf and Hard of Hearing Infants and Children. It will support and enhance Delaware's statewide newborn and infant birth hearing screening, evaluation and diagnosis, and early intervention services system of care through collaboration and establishing Deaf Mentor programs for families.

**Criterion 5: Resources/Capabilities**

The Delaware EHDI Program has several resources and the capacity to implement this four year project. Delaware has a Governor appointed EHDI Advisory Board that has been active since calendar Yr. 2012. Our board consist of Governor appointed board members who are required to serve on the EHDI Advisory Board who are: Audiologist, Speech-language pathologist, Pediatrician/neonatologist, Otolaryngologist, Neonatal nurse, a designee from the Secretary of the Department of Health and Social Service, an adult who is deaf or hard of hearing, Parent of a child with a hearing loss, Teacher of children with hearing loss A representative from the designated agency responsible for the IDEA Part C, Part B 619 Department of Education and a representative from the Statewide Programs for Deaf and Hard of Hearing. The board is chaired by our Chapter Champion Dr. Carlos Duran who also works at the largest birthing facility in the state of Delaware. He is very influential in our state and has a rapport with Pediatricians throughout all three counties (Kent, Sussex, and New Castle County). The EHDI Program has a strong partnership with our Part C Early Intervention Program known as Child Development Watch and our Part B 619 Department of Education. Both Part C and Part B representation serves on the EHDI Advisory board along with adults who are Deaf/Hard of Hearing and parents of children who are also Deaf/Hard of Hearing. Our EHDI Advisory board has the capacity to engage professionals throughout the state and the ability to provide recommendations to make changes to improve the EHDI System in our state through the Public Health State Secretary. The state of Delaware has the support from the Delaware Statewide Programs for Deaf and Hard of Hearing Deaf Blind Program, which has two active mentorship program. One through Statewide Programs Outreach focusing on families and one at Delaware School for the Deaf (DSD) for students. The state of Delaware has documented legislation under Title 16 Health and Safety Regulatory Provisions Concerning Public Health Chapter 8A. Universal Newborn and Infant Hearing Screening, Tracking and Intervention. The Delaware EHDI Program will utilize these resources to align with the 1-3-6 Timeline which is recommended by the CDC. These resources will also support our effort in timely screening, diagnosis and intervention for infants and children up to age 3. Delaware will be able to meet the four year project's expectations and strengthen the inclusion of family engagement and health professionals as well as all Early Hearing Detection and Intervention (EHDI) Service Providers.

The Delaware EHDI Program under the guidance of the Quality Improvement/Quality Assurance subcommittee of the EHDI Advisory Board will use continuous quality improvement techniques

as the primary tool to problem solve barriers in the delivery of EHDI Programming. The focus will be on whether or not the strategies that are being used would benefit from enhancement. Using the Plan Do Study and Act (PDSA) cycles of small tests of change the Delaware EHDI Program will continue to achieve measurable improvements in the Loss to Follow Up Rate (LTFU) rate.

### **Criterion 6: Support Requested**

Delaware has developed a proposed budget that is reasonable for each year of the 4 year project. The allocation for adequate timing and funding for staffing has been provided in a detailed format. The budget narrative provides a detail description of the total costs for expenses of 1-2 staff to attend the annual EHDI Meeting. This also includes a family leader from a parent lead organization. Delaware will allocate at a minimum 25% of funding to family support and engagement for the success of this 4 year project. Delaware will allocate 5% of the budget to purchase or maintain hearing screening equipment if needed by our 7 birth facilities or our Midwifery Council. Delaware has allocated a portion of the funding for accommodation for communication access through interpretive services and translation.

### **Goals for the 4 years of this Early Hearing Detection and Intervention Project.**

**Goal 1: By March 31, 2024, Delaware will utilize Yr. 2017 CDC – HSFS baseline data to increase by 1 percent from baseline the proportion of newborns screened no later than 1 month of age.**

Aim 1: By December 31, 2019 develop a site visit schedule for the calendar year 2020 which aligns with our Nemours A.I. DuPont Hospital for Children (AIDHC) Metabolic Program to conduct collaborative quarterly Quality Improvement (QI) site visits to improve hearing screening 1-3-6 Timeline.

Aim 2: Ensure infants are all screened at birth in the birth facility and results are entered into Oz Systems or reported to the EHDI Program within 10 days.

**Goal 2: By March 31, 2024 The EHDI Program will increase family engagement and support through a parent lead organization –Hands and Voices Guide By Your Side and the support from Delaware Statewide Program for the DHH/DB Mentor Program.**

Aim 1: By April 30, 2020, develop a contract with a parent lead organization –Hands and Voices Guide by Your Side.

Aim 2: By May 1, 2020 implement a Letter of Agreement between Hands and Voices and Delaware Statewide Program for the DHH/DB Mentor Program to enhance Delaware’s Family to Family support and engagement initiatives.

**Goal 3: By March 31, 2024, Strengthen capacity to provide family support and engage families with children who are Deaf/Hard of Hearing (DHH) as well as adults who are DHH throughout the EHDI System with the support of Delaware Statewide Programs for the Deaf Hard of Hearing & Deaf-Blind and a parent lead organization-Hands and Voices Guide By Your Side.**

Aim 1: The EHDI Program in partnership with Title V will assess and coordination across early childhood programs in an effort to improve services such as IDEA Part C, Home Visiting, and Head Start Program.

Aim 2: By March 31, 2020, the EHDI Program in partnership with the EHDI Advisory Board will lead the efforts in developing a crosswalk on service delivery approach on extending family to family support for families with children who are D/HH.

Aim 3: By June 30, 2020 schedule trainings and learning communities in collaboration with the Statewide Programs D/HH DB Mentoring Program for parents and early childhood program providers on knowledge of the EHDI System of Care.

Aim 4: By March 31, 2024, use quality improvement methodology, in partnership with statewide parent support organizations, Delaware EHDI Board, the Quality Improvement Sub-committee, EHDI Stakeholders and enhance Provider engagement throughout the state of Delaware to reduce the loss to follow-up rate between inpatient screening and initial out-patient follow up.

Delaware has progressed over the years with our Loss to Follow Up Rate (LTFU) rate. If awarded the HRSA-20-047 funding opportunity, Delaware will be able to continue to improve and enhance our Family-to-Family initiatives with our parent lead organization –Delaware’s Hands and Voices Guide By Your Side. This funding opportunity is very timely for our state. With staff transitioning in Title V this four year project will afford the EHDI Program to educate Title V partners, DOE and medical practitioners of the EHDI System of Service.