

West Virginia Department of Health and Human Resources  
Bureau for Public Health  
Office of Maternal, Child and Family Health  
Division of Research, Evaluation and Planning  
Newborn Hearing Screening Program

FOA# HRSA-20-047  
*Early Hearing Detection and Intervention Program*

**NARRATIVE**  
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The West Virginia Department of Health and Human Resources, Office of Maternal, Child and Family Health offers notice of intent to apply for the New and Competing Continuation Grant funding by the Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs (FOA# HRSA-20-047) Early Hearing Detection and Intervention Program.

## **INTRODUCTION**

The purpose of the Newborn Hearing Screening Program (NHS) is to maintain a comprehensive Early Hearing Detection and Intervention (EHDI) System in West Virginia (WV). In 1998, WV passed legislation specifying that, as of July 1, 2000, all licensed birthing facilities were required to screen newborns for hearing loss before discharge, and to provide information to parents of newborns birthed at home or in non-hospital facilities of the need to obtain hearing screening within the first month of life. The State Legislature amended Chapter Sixteen of the Code of WV by adding Articles 22A and 22B. Article 22A requires the testing of newborn infants for hearing loss. Article 22B codifies the WV Birth Score System and requires that all birthing facilities, attending physicians, and other persons attending a birth ensure that a risk assessment is completed on all resident births.

The law established guidelines for fees associated with Universal Newborn Hearing Screening (UNHS) and required that inpatient screening be a covered benefit reimbursable by all health insurers and Medicaid. The WV Bureau for Public Health (BPH), Office of Maternal, Child and Family Health (OMCFH) is the State's office which houses Early Intervention (EI)/Part C – Birth To Three (BTT) and the Children with Special Health Care Needs Program (CSHCN). OMCFH moved NHS to the Division of Research, Evaluation and Planning in 2017. Initial responsibilities included rule-making, authorization to establish fees for screening, guidelines for testing protocol, reporting and referral requirements. The legislation did not, however, include funding to support Program development and administration.

The NHS has continually expanded to include services necessary to strive to meet the recommendations of the Joint Committee on Infant Hearing (JCIH), Health Resources and Services Administration (HRSA), and the Centers for Disease Control and Prevention (CDC) to ensure infants are not only screened for hearing loss before one month of age, but also receive timely diagnostic evaluation by three months of age and referral and enrollment into EI, when needed, by six months of age. Hospital screening rates have remained consistently high since the start of the Program. However, increasing the timeliness of audiological diagnostic evaluations and referral and enrollment into early intervention has proven to be difficult areas to address effectively to create change.

The NHS has participated in multiple opportunities provided by HRSA and the National Center for Hearing Assessment and Management (NCHAM) to discover ways to create positive change within the Program. The NHS was part of the Center for Cultural Competency Learning Collaborative, which focused on creating and implementing changes to ensure that services are provided with cultural competence and to provide education to stakeholders on the importance of cultural competency in care systems. The National Initiative for Children's Healthcare Quality's (NICHQ) Improving Hearing Screening and Intervention Systems (IHSIS) Collaborative was utilized to learn the importance of Quality Improvement (QI) and how to imbed the ideas of QI into the Program for continual assessment and growth. The NHS has been partnering with West

Virginia Hands & Voices (WVH&V) consistently since 2012 to ensure that parents of children who are deaf or hard of hearing have a voice in decision making processes and to ensure that providers across the state are able to understand the needs of families. In 2018, that partnership was formalized when NHS contracted with WVH&V to implement the Parent Support Program (PSP). In 2016, the NHS designed and implemented a new data system to create a more accurate account of the flow of the process in the State and help determine areas that need improvement. Allowing providers to submit diagnostic evaluations electronically to the NHS data system will also assist in the decrease of infants lost to documentation.

The NHS has worked over the last years to improve the quality of services provided and continues to participate in national educational opportunities and to evaluate statewide needs to assess areas where QI can be used to develop activities, policies and procedures that support the needs of infants and their families in West Virginia.

## **NEEDS ASSESSMENT**

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Though screening and referral rates are above average, all infants who were not screened because of equipment failure, Neonatal Intensive Care Unit (NICU) admission or failure of the initial screen are not always receiving timely, appropriate follow-up. 2016 data indicate that 39% of infants who referred or missed initial hearing screening were lost to follow up.

Follow-up is difficult in part because WV is the second most rural state in the nation. Twenty (20) of West Virginia's fifty-five (55) counties are 100% rural according to the Census Bureau definition, with an additional fourteen (14) designated as 75% rural.

West Virginia is surrounded by Pennsylvania, Maryland, Virginia, Ohio and Kentucky and is commonly referred to as a South Atlantic State. The Appalachian Mountains extend through the eastern portion of the State, giving WV the highest elevation of any state east of the Mississippi River. Appalachia is a 200,000 square mile region spanning thirteen (13) states from southern New York to northern Mississippi. West Virginia is the only state in which all fifty-five (55) counties lie entirely within the Appalachian Region.

Geographically, the region is characterized as having a rolling topography with rugged ridges and hilltops reaching upwards of 4,000 feet with remote valleys in between. The valleys often feel isolated and separated from the urbanized areas. It is this isolated feeling, ingrained in the landscape that has contributed to the strong sense of independence and family among Appalachians. For as much beauty as the geography brings, it can also be treacherous and impassable, causing a major barrier in accessing health care. Narrow, winding roads, inclement weather conditions in the winter months, and absence of public transportation outside of urbanized areas compounds the problem of health care access.

When defining Appalachia, it is important not only to discuss the geography of the region, but the culture as well. While the geography of Appalachia has presented many barriers and to some extent has cut the region off from mainstream America, it has also contributed to preserving the region's rich cultural heritage. Culturally, Appalachians have core values and beliefs such as individualism and self-reliance. The people are products of their history and the beliefs of their forefathers. These same core values, which breed strong ties to family and tradition, also reflect

detrimental health behaviors, the effects of conservative religion on medical care use, and feelings of alienation from national society. The detrimental health behaviors often result in poor birth outcomes.

Population estimates from the 2010 Census reported that 93.9% of WV residents are Caucasian, 3.4% Black or African American, 0.2% American Indian and Alaska Native, 0.7% Asian, and 3% some other race and two or more races 1.5%. The population has fluctuated between 1.8 and 2 million over the last fifty (50) years. The rate of resident births has declined more than half from 1950 to present day.

For reporting purposes of this grant application, information is based upon data from the NHS Data System, which is linked to the Birth Score Office (BSO) data system. This is beneficial due to the BSO being the initial source of the infant hearing screening hospital data. Currently, the data flow is thus: birthing facilities electronically submit hearing data to the BSO and then the BSO pushes that data into the NHS Data System. This linkage is also vital because it allows the BSO the ability to share any hearing screening updates submitted by birthing facilities (including NICUs) and benefits from the data reconciliation process between the BSO and Vital Statistics.

Each year the BSO reports not receiving score card data for approximately 600 to 800 infants. This represents approximately 3.3% of infants born in West Virginia. To aid in the solution of this problem, the BSO implemented statewide electronic reporting of the score card data. The BSO now receives data from hospitals in a more timely way and is able to follow-up more frequently with hospitals who are not reporting as required. Infants who are transferred to Neonatal Intensive Care Unit (NICU) are generally reported as not screened by the birthing facility and then are later screened within the NICU at the time of discharge. All West Virginia birthing facilities have a minimum of two trained staff with proven competence in newborn hearing screening and referral.

At the present time, there are 24 birthing facilities in WV. Data from WV Vital Statistics indicate there were 19,889 residence births in the State in 2016. The 2016 data is used herein as the baseline to determine the goals and activities needed to create positive change in the NHS system. In 2016, 96.4% of infants were screened for hearing loss. Of those who referred or missed the initial screening, 39% were undetermined or undocumented diagnosis and considered lost to follow up. Of the 4 infants who were found to have hearing loss, all were referred to EI and 2 were enrolled in EI.

## **METHODOLOGY**

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NHS has adopted goals set forth by Healthy People 2020 and the Centers for Disease Control and Prevention (CDC), recommending that all newborns be screened for hearing loss prior to one (1) month of age, have an audiological evaluation by three (3) months of age and have appropriate intervention services by six (6) months of age (1-3-6 Plan). NHS will follow recommendations provided by the National Initiative for Children's Healthcare Quality (NICHQ) to enhance the States EHDI performance in meeting screening, diagnosis and intervention goals. NHS will work with hospitals, primary care providers, audiologists, ENTs, interventionists and families to reduce loss to follow-up. To help promote and achieve these important time frames,

NHS continually provides educational materials to medical and service providers, families, and communities.

The ultimate goal of the NHS is to identify and provide care to 100% of infants needing services and not lose children to follow-up. NHS will focus on activities to meet the goals as stated in the application:

1. Increase the number of infants who receive hearing screen no later than 1 month of age
  - a. Increase hospital screener education on the importance of meeting the 1 month goal of hearing screening
  - b. Increase medical providers' knowledge of the importance of meeting the 1 month goal of hearing screening
  - c. Improve family and community knowledge of the importance of meeting the 1 month hearing screening goal;
2. Increase the number of infants that receive diagnostic audiological evaluation no later than 3 months of age
  - a. Increase provider and family knowledge of the importance of receiving diagnostic evaluation by 3 months of age
  - b. Provide education to audiologists on the use of NHS Data System Audiology Portal for timely reporting of diagnostic evaluations;
3. Increase the number of infants identified to be Deaf/Hard of Hearing (DHH) enrolled in EI no later than 6 months of age
  - a. Develop enhanced data sharing protocol with EI service providers;
4. Increase the number of families enrolled in family-to-family support services no later than 6 months of age
  - a. Collaborate with family support agencies to provide services and networking to families;
5. Increase the number of families enrolled in DHH adult-to-family support services no later than 6 months of age
  - a. Collaborate with DHH adults to develop and implement DHH adult-to-family support services;
6. Increase the number of health professionals and service providers trained on key aspects of the EHDI system
  - a. Engage health professionals and service providers in education on the key aspects of NHS;
7. Expand NHS infrastructure for data collection and reporting for hearing screening of children up to the age of 3
  - a. Develop and implement a formal collaboration with other agencies to monitor hearing screening up to age 3;
8. Improve NHS methods of ensuring development of policies to address diversity, inclusion, and cultural competency within the EHDI system
  - a. Develop and implement diversity, inclusion, and cultural competency in the EHDI system;
9. Identify existing challenges in NHS and use QI approach to address the needs of the EHDI system.

- a. Utilize QI approach to address NHS needs for provider outreach and education, and family engagement and support; and
10. Collaborate with state and other agencies to enhance education and data collection in meeting the 1-3-6 EHDI goal.
- a. Develop formalized collaborations with agencies who see pregnant women, infants, and families to educate families on the 1-3-6 goal and for data sharing purposes.

The current work flow is as follows: infant hearing screening data is submitted to the BSO electronically from the birthing facilities; a West Virginia Hands & Voices (WVH&V) Parent Support Specialist (PSS) sends out an informational reminder notecard to families with infants who missed or referred initial hearing screen; PSS sends out initial informational and welcoming letter with parent response form and SASE to families with infants who still need hearing screen or diagnostic evaluation; parent letter responses are returned to NHS Program Director who uses physician fax back form and phone calls to gather data on hearing status while PSS makes phone calls to families to gather data on hearing status and offer support services; PSS sends out final letter to families with educational information on the importance of the 1-3-6 timeline and offering support services. During this process, the data system provides lists of infants needing specific follow up as they go through the process and the PSS and NHS Coordinator are entering data as it becomes available through contacts with families and professionals. Families will be followed until the data for that year is required for reporting or the family requests not to be contacted further.

Strategies for achieving identified goals and objectives will continue to be actualized using NHS staff, NHS Advisory, WVH&V Parent Support Program, BSO, health care providers, audiologists and community involvement. OMCFH will continue to oversee the completion of activities through coordination of internal systems such as web-based collection of data and monitoring referral processes. Referrals are now sent only to BTT, the WV EI program, which also manages the West Virginia School for the Deaf (WVSD) Outreach Program across the state. NHS and the WVH&V PSP are also currently working on a Family Package for families of children who are found to be DHH that includes referrals to various resources for communication modalities and support/networking organizations.

The WVH&V Parent Support Program works with families to provide social activities, family-to-family and family-to-professional networking, and educational workshops. Efforts are made not just to provide support through the program, but to encourage families to build relationships amongst themselves for continued support as their children grow. Parent Support Specialists also present to professionals on the importance of family engagement and communication with families.

The NHS Advisory Committee will continue to be an integral part of the creation of ideas and activities that will enable the NHS to meet Program goals. The addition of representation from several new agencies and establishing 25% of participants as parents of children who are deaf or hard of hearing or deaf adults will ensure that the needs of families and infants are at the forefront of our activities. The Advisory will meet at least twice each year, in the spring and fall.

Advisory members will continue to collaborate on various work groups and QI Teams to address barriers.

The NHS will develop a data sharing protocol with BTT to address timely referral and enrollment in early intervention. The data that is shared will assist both programs in discovering when infants are not moving through the process to meet the 1-3-6 guidelines. There has always been informal data sharing between the NHS and BTT since both are housed within the OMCFH. However, a formal protocol will ensure that data sharing occurs within a certain timeframe and secures the process for future employees of both programs.

In the effort to determine how best to improve program elements, NHS will engage in the QI process of PDSAs to test ideas for positive value prior to implementation. NHS has chosen to focus on provider outreach and education, and family engagement and family support. These areas represent important aspects of the NHS, which are in need of continual growth to meet the needs of the families served.

The NHS receives data directly from the BSO, which is matched with vital statistics information. The NHS will explore other data matching sources, such as newborn screening, which is also housed within the OMCFH and the immunization registry in WV as a means to address the lost to follow-up population and decrease the percentage of families otherwise unable to be reached.

The CSHCN Program administered through OMCFH, assists families that have children with special health care needs and their doctor with developing a shared plan of care, finding and organizing resources, understanding and utilizing insurance to maximize benefits and meeting the child's special health care needs close to home. CSHCN is currently working on revisions to the Kids First: Hearing Services' program that allows them the ability to provide hearing aids for qualifying children. In addition to WV Medicaid, CSHCN and NHS continue to work with the WV Children's Health Insurance Program (CHIP) and private insurers regarding hearing screening, adequate reimbursement for audiological services, amplification and data sharing.

The National Center for Hearing Assessment and Management (NCHAM) is a continual source of education and assistance to the NHS. The NHS will continue to take advantage of opportunities offered by NCHAM, including the new Family Leadership in Language and Learning Center.

The NHS is supported by the large infrastructure housed within the OMCFH. The NHS engages in QI methodology to improve Program outcomes. Leadership staff offers valuable linkages to other programs within the office that can be of assistance to NHS as community partners.

The NHS is partially supported by the Office's Title V Maternal and Child Health Block Grant. The NHS would be sustained by OMCFH should this funding opportunity not be available.

Since its inception, significant progress has been made in achieving goals set forth by NHS. In order to further improve follow-up, current data collection was transferred to the NHS Data System, which was designed specifically for the needs of NHS.

## WORK PLAN

Using the methodology outlined above, the NHS will engage in activities to meet the outlined goals and activities.

### Activity Priorities Necessary for Meeting Goals:

- Develop formal collaborative relationships with appropriate agencies, including BTT, CSHCN, WIC, Early Head Start, and Health Check;
- Address missing representation on the Advisory Committee;
- Develop data sharing agreements with partner agencies;
- Improve electronic reporting of diagnostic evaluations for audiologists;
- Provide trainings for providers and families; and
- Utilize WVH&V for family support.

The goals and aims outlined below will remain the focus of the work. However, as barriers to planned activities arise or evaluation determines current activities are not successful, QI methodology will be applied to determine new ways to reach the stated goals.

| Goal  | Aim   | Potential Community Partner(s)   |
|---|---|--|
| Increase from 90% to 95% the number of infants that receive newborn hearing screen no later than 1 month of age.              | <ol style="list-style-type: none"> <li>1. Increase hospital screener education on the importance of meeting the 1 month goal of hearing screening.</li> <li>2. Increase medical providers (NICU staff, audiologists, and physicians) knowledge of the importance of meeting the 1 month goal of hearing screening.</li> <li>3. Improve family and community knowledge of the importance of meeting the 1 month hearing screening goal.</li> </ol> | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |
| Increase from 15% to 80% the number of infants that receive diagnostic audiological evaluation no later than 3 months of age. | <ol style="list-style-type: none"> <li>1. Increase provider and family knowledge of the importance of receiving diagnostic evaluation by 3 months of age.</li> </ol>  | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |

|   |   |  |
|---|---|--|
|   | 2. Provide education to audiologists on the use of NHS Data System Audiology Portal for timely reporting of diagnostic evaluations. |  |
| Increase from 25% to 80% the number of infants identified to be DHH enrolled in EI no later than 6 months of age.                         | 1. Develop enhanced data sharing protocol with EI service providers.  | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |
| Increase by 20% the number of families enrolled in family-to-family support services no later than 6 months of age.                       | 1. Collaborate with family support agencies to provide services and networking to families.   | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |
| Increase by 10% the number of families enrolled in DHH adult-to-family support services no later than 6 months of age.                    | 1. Collaborate with DHH adults to develop and implement DHH adult-to-family support services.                                       | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |
| Increase by 10% from Year 1 baseline the number of health professionals and service providers trained on key aspects of the EHDI Program. | 1. Engage health professionals and service providers in education on the key aspects of NHS.  | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |
| Expand NHS infrastructure for data collection and reporting for hearing screening of children up to age 3.                                | 1. Develop and implement a formal collaboration with other agencies to monitor hearing screening up to age 3.                       | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |
| Improve NHS methods of ensuring development of policies to address diversity, inclusion, and cultural competency within the EHDI system.  | 1. Develop and implement diversity, inclusion, and cultural competency in the EHDI system.  | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |
| Identify existing challenges in NHS and use a QI approach to address the needs of the EHDI  | 1. Utilize QI approach to address NHS needs for provider outreach and education, and family   | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program                     |

| system.  | engagement and support.   | Providers, Families  |
|--|---|--|
| Collaborate with state and other agencies to enhance education and data collection in meeting the 1-3-6 EHDI goal. | 1. Develop formalized collaborations with agencies who see pregnant women, infants, and families to educate families on the 1-3-6 goal and for data sharing purposes. | Pediatric Care Providers, Audiologists, Home Visitation Programs, BTT Providers, WVH&V, State Agency Program Providers, Families |

Key to achieving the goals outlined above are collaborative efforts with other agencies and organizations for the purpose of providing education to providers and families, and also for the purpose of data sharing to capture children’s hearing screening results up to age 3.

**RESOLUTION OF CHALLENGES**

Identifying infants at greatest risk for health and development problems and ensuring that these children have access to appropriate health and special care systems are ongoing concerns for WV State health officials. A collaborative process has been used for the planning of NHS and the development of various systems for joint case findings, referrals, communication and care coordination which are essential for the implementation of the NHS Program. These partnerships are effective in identifying system barriers for infants and families and removing those barriers through system change. Joint efforts assure meeting the family centered and culturally diverse needs of all populations served by OMCFH.

In this regard, OMCFH and NHS work collaboratively with the BSO within the WVU Department of Pediatrics in order to support newborn developmental risk and hearing screening initiatives. West Virginia State Code mandates the responsibility to screen all infants at birth. This screening opportunity allows WV to collect information on development risk and delay, hearing loss and the risk of post neonatal death on one screening/collection instrument, BSC. The screening information then triggers follow-up activities, which include services through the WVH&V PSP for follow up and referrals.

The primary objective of the BSO is to coordinate a seamless infant risk screening system that identifies newborns at greatest risk for poor health outcomes and possibly preventable death between one (1) month and one (1) year of age. Further, infants identified as High Birth Score are to receive an accelerated number of pediatric visits, six (6) in the first six (6) months of life, which exceeds American Academy of Pediatrics (AAP) recommendations.

NHS still faces the major challenges that have been present historically, which include; timely diagnostic follow-up, audiologists with limited experience in the diagnosis of infants, data collection, and families and infants lost to follow-up.

The most impactful resolution for NHS in this past grant cycle was the contract with WVH&V for the implementation of the Parent Support Program (PSP). The requirement from HRSA that monies be spent on family-to-family support created the ability for NHS to obtain a contractual agreement with WVH&V for their creation of the PSP. In 2016, the percentage of infants who received hearing diagnosis by 3 months of age was 14% (with similar numbers in 2017). The WVH&V PSP was implemented in 2018, and that year the percentage of infants diagnosed by 3 months of age increased to 44%. No other change to the provision of NHS services has created this kind of positive change.

The reason for the success is multi-faceted. As the initial point of contact for families after the hospital experience, families receive information from other parents who have shared experiences and are able to share their thoughts and emotions as they also guide them through the screening and diagnostic process. WVH&V PSP is also seeing such success through their efforts at community education and engagement. Families have access to education on the importance of follow up, self-advocacy, and modes of communication. In addition, the family social and networking events across the state allow families the opportunity to engage with one another and create a support network.

The implementation of the NHS Data System, which was specifically built for the needs of NHS, has also had an impact on the operation of NHS. The data system allows the seamless flow of data from the BSO to NHS and the WVH&V PSP and facilitates timely follow up with notifications concerning next steps for infants and engagement with families. With the addition of the audiology portal within the data system and the education provided to audiologists, NHS hopes to see a significant reduction in the percentage of infants lost to documentation. The data system also allows creation of reports on data useful to the QI PDSA approach that NHS will use in the coming grant cycle as a method of program improvement.

NHS still houses OAE screening equipment for use by birthing facilities when they experience equipment issues. However, most facilities are now taking advantage of equipment distributors ability to loan equipment in times of need and NHS has not seen much use of the loaner equipment over the past several years. Discovering how this equipment can be used to assist in the identification of the need for further testing is an important goal. NHS will work with partners to determine how best to utilize this equipment in the future.

An assessment of Audiological and Ear, Nose, and Throat (ENT) provider availability found that WV has 16 audiologists and ENT providers capable of diagnosing infants and toddlers under the age of three (3) years. This ensures that parents, by way of NHS, program partners, and health care professionals, are provided knowledge of the latest audiology services available. Providers are polled periodically and the web-based Audiology Service Availability Guide is updated at least quarterly to ensure the latest information is available. The web-based version of the Audiology Service Availability Guide is linked to the RFTS and NHS websites. The Guide includes a map of WV that includes county specific service availability as well as those in bordering states.

Part of addressing the challenges in audiological service in the state is to ensure that NHS educated audiologists on their obligation to report to NHS for thorough follow up and their legal

obligation to refer infants to BTT. By presenting at audiology conferences within the state and in visiting audiologists, NHS will work to ensure that audiologists understand their role in reporting and how to appropriately make those referrals.

Audiologists and medical providers will be educated on the importance of providing unbiased information to families as they navigate the process of determining hearing status. Because hearing loss is low incident, many professionals are unfamiliar with the impact of the diagnosis on families and the options that are available to them. Audiologists in the state seem to be providing families with a narrow set of options, determined by their services instead of allowing families the opportunity to explore options and make choices based on what is best for their family. Providing education on approaching families with unbiased and complete information is important, as well as making needed referrals to programs and organizations that can offer more insight for families.

In order to address the gaps in qualified audiological providers, a collaborative effort between NHS and CSHCN will work to develop pop up audiology clinics around the state in the areas where there are no experienced pediatric audiology providers. Research of the need for audiological support in specific areas will be done to determine best impact of these clinics. This project will help address the issue of low availability of audiologists, but also the barriers of long travel times for families and long wait times for appointments.

In addition to CSHCN, NHS will collaborate with partners such as WIC, Early Head Start, Home Visitation, BTT, and Health Check to further educate families and professionals on the importance of the 1-3-6 goal and their respective roles in assisting families in that process. The more aspects of family care that provide education on the importance of learning hearing status, the more families will understand the impact of follow up.

Although WV birthing facilities consistently have a high rate of initial screening, NHS is concerned with the way in which information is presented to families at the time of pass/refer. In the past several years, NHS has worked to develop new and updated materials for birthing facilities to use to provide education to families, allowing for consistency across the state. In addition to providing those resources, NHS will visit the birthing facilities and provide education to facility staff on newborn hearing screening.

NHS is choosing to engage in QI Plan Do Study Act (PDSA) work to address the challenges in provider outreach and education and family engagement and support. This approach will be utilized to address some of the challenges detailed above and discover the most effective methods of resolving issues facing NHS.

## **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

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The NHS has the opportunity to monitor infants and their newborn hearing screening progress through a joint collaboration with the BSO, the audiologists and the programs that infants with hearing loss are referred to for further services. The partnerships developed ensure that any infant who does not pass their hearing screen are linked to appropriate referral sources in a timely manner. With the data sharing capabilities between birthing facilities, West Virginia Center for Health Statistics, BSO and NHS, a strong screening process has been developed.

With the support of the NHS Advisory Committee, ongoing plans for improved screening processes, enhanced data collection capabilities and decreased lost to follow-up rates will ensure the continuation of a strong statewide network in West Virginia dedicated to NHS.

The BSO provides detailed annual reports to NHS outlining program priorities, analysis of Birth Score data, annual program highlights and projected goals for the following year. The report describes the strong collaborative process which serves to ensure a seamless process of securing infants who do not receive or do not pass the newborn hearing screening receive timely follow-up and appropriate intervention.

The new data system, implemented in 2015, enables the NHS to have solid data for evaluation. The NHS is now better able to determine the age at which infants are being screened, receiving diagnosis and being referred to BTT.

Within OMCFH, through the Division of Research, Evaluation, and Planning, an full-time epidemiologist is available to assist with NHS data review and monitoring. The availability of an epidemiologist to assist in data analysis will allow NHS a more in depth understanding of data collection practices and the use of that data for continued development and quality improvement of NHS practices. This has allowed NHS to work on the development of family and professional surveys to determine what areas of the EHDI system need development and improvement.

The NHS data system audiology portal further strengthens the efficacy of the data system and allows for more timely reporting by audiological providers to NHS, ensuring that infants needing follow up services and linkages receive such within the 1-3-6 timeline.

## **ORGANIZATIONAL INFORMATION**

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The NHS is housed in the West Virginia Department of Health and Human Resources, Bureau for Public Health, Office of Maternal, Child and Family Health, Division of Research, Evaluation, and Planning.

The OMCFH is the WV Title V agency and is housed within the Bureau for Public Health under the umbrella of the Department of Health and Human Resources. This structure lends itself to easily interact and collaborate with the Bureau for Children and Families, the Bureau for Medical Services (Medicaid), the Office of Nutrition Services (WIC) and the Health Statistics Center (Vital Statistics) to name a few. Every five years, the OMCFH conducts the required Title V Needs Assessment. The Needs Assessment is used to evaluate competing factors which impact health delivery services from the program level and drives activities to improve the health status of the maternal and child health population.

The OMCFH involves multiple stakeholders across WV to develop and support interventions that will achieve positive results. These partnerships collaborate around data collection activities, evaluate availability of care, service utilization and the quality of health services for the maternal and child health populations. The Office maximizes the use of funding streams from state and federal dollars to administer population-based surveillance and service systems, work in partnership with other agencies to not duplicate services, provide safety-net services for gaps in the delivery system, support home visitation services that strengthen families and provide

capacity for data collection and analysis. Allocation of resources is based on need that takes into consideration other available resources, population served and desired outcomes.

The OMCFH has been acknowledged for its positive partnerships across the State including the medical community, the University System, the State Department of Education, the Perinatal Partnership and March of Dimes, among others. The OMCFH is known for its willingness to engage and participate alongside stakeholders in designing systems of care to serve the maternal and child health population. The Office knows that resources are scarce, and WV cannot afford to duplicate existing systems that are working well. OMCFH also understands that it must join other stakeholders to achieve goals.

The NHS Advisory Committee is the primary collaborative structure. According to the State Code of West Virginia, representation on the committee must include at least one member from BTT, the health insurance industry, West Virginia Department of Education, WVSDDB, a parent of a hearing-impaired child, West Virginia Hospital Association, an otolaryngologist or otologist, an audiologist, a pediatrician, a speech pathologist and the West Virginia Commission for the deaf and Hard of Hearing (WVCDHH). In addition to the role representation mandated by the Code, the NHS has made additions to the Advisory important to ensuring provision of appropriate services, including adults who are deaf or hard of hearing. In 2019, the NHS will add further representation to the Advisory to assist in Program decision making and areas of focus within the EHDI system, including the increase of families and adults who are deaf or hard of hearing to 25% of the Advisory. Stated goals, aims and activities are all areas that the Advisory has been focusing on over the past year.

The BTT supports a parent coordinator at each regional site to foster communication and sharing of experiences. The parent coordinator, or Parent Partner, has the responsibility of establishing working relationships with existing parent information and support groups, representing BTT on relevant interagency committees and assisting with carrying out family-to-family components of the BTT grant. This is particularly important for infants and toddlers referred to BTT due to hearing loss.

The BTT provides information to families to assist them with decision making on communication opportunities for their infant. The BTT website is updated on a regular basis to provide links to current issues and information. Family-to-family components of BTT, which the Parent Partner may help with, are linkages of families to needed formal and informal resources, including structured activities to connect parents of eligible children with other parents of children with special needs; family leadership and education opportunities for families participating in BTT; and linking families to other resources, including financial resources, based on individual family interest and/or need.

The addition of the utilization of WVH&V as a family support system ensures that families are receiving support from others who have shared the same experiences. This family support gives families the opportunity to see the importance of timely diagnosis and early intervention and provide the emotional support that is vital to family decision making.

The BSO continues to support NHS through data collection of the initial hospital screenings reported on the birth score cards. The NHS and BSO staff will continue to collaborate on training hospital screening staff on new infant hearing screening educational opportunities.

Annually, each birthing facility validates hospital contact personnel and identifies issues/concerns with screening and referral procedures for infants. The BSO worked closely with hospital staff to implement electronic reporting of the BSC with West Virginia birthing facilities in 2013. Electronic reporting enables the BSO to report hearing screening results to NHS within a shorter timeframe, allowing NHS staff to more quickly offer support and services to families. The NHS data system is linked to the BSO data system and receives infant hearing screening data the same day as reported by the birthing facilities.

The OMCFH was assigned lead agency responsibility for coordination, development and implementation of the federally mandated West Virginia Home Visitation Program (WVHVP). The primary focus of the WVHVP is to increase infrastructure within West Virginia to expand home visitation services to clients residing in identified highest at-risk counties. The WVHVP will improve community involvement and support positive child and family health, learning and development outcomes.

The NHS was notified December 2010 that West Virginia was selected to collaborate with the Early Childhood Hearing Outreach (ECHO) Initiative. Since that time, the NHS staff has collaborated with the ECHO Outreach Coordinator, National Center for Hearing Assessment and Management (NCHAM) at Utah State University, and participated in planning sessions, webinars and teleconferences to begin collaboration with Early Head Start providers for implementation of the ECHO Initiative in West Virginia. The NHS will continue to provide support to the ECHO Initiative sites in West Virginia. The ECHO Initiative will assist NHS in transitioning infants to follow-up services to avoid a potential gap in services during which time the child could experience unrecognized hearing deficits. This partnership will enhance the NHS's ability to collaborate in efforts to extend infrastructure to screen and collect data for children up to 3 years of age.

The NHS will continue to monitor all goals, objectives and activities, while working on the QI methodology. West Virginia will work to achieve 100% identification and improve the follow-up rate for all infants born in the State to ensure infants receive timely hearing screening, audiological evaluation by a qualified provider and appropriate intervention within recommended time frames. Without timely diagnosis and entrance into early intervention, children with hearing loss may suffer developmental delays in language, cognitive and social skills that could prevent success in academic and occupational achievement.