

# **PROJECT NARRATIVE**

## **Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening**

**NC Department of Health and Human Services**

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## Acronyms

AAP	American Academy of Pediatrics
BHSM	Better Hearing and Speech Month
CARE	Counseling, Aural Rehabilitation, and Education
CDC	Centers for Disease Control and Prevention
CHAC	Child Health Audiology Consultant
CDSA	Children’s Development Services Agency
CPHQ	Center for Public Health Quality
CQI	Continuous Quality Improvement
C&Y	NC Division of Public Health, Children and Youth Branch
DHHS	Department of Health and Human Services
DPH	NC Division of Public Health
DPI	NC Department of Public Instruction
ECU	East Carolina University
EHDI	Early Hearing Detection and Intervention
EHDI-IS	Early Hearing Detection and Intervention Information System (Hearing Link)
EHDI-PALS	EHDI – Pediatric Audiological Links to Service
EIDHH	Early Intervention for Children Who Are Deaf or Hard of Hearing
EI	Part C Early Intervention
FFP	Federal Financial Participation from Title XIX Medical Assistance Program (Medicaid)
HPSA	Health Professional Shortage Areas
HRSA	Health Resources and Services Administration
JCIH	Joint Committee on Infant Hearing
LHD	Local Health Department
LQI	Local Quality Improvement
LTF/D	Loss to Follow-up/Documentation
MCHB	Maternal and Child Health Bureau
MIECHV	Maternal, Infant and Early Childhood Home Visiting Program
MUA	Medically Underserved Areas
NC-EHDI	North Carolina’s Early Hearing Detection and Intervention Program
NCHAM	National Center for Hearing Assessment and Management
NCITP	North Carolina’s Infant Toddler Program
NICHQ	National Initiative for Children’s Healthcare Quality
PCP	Primary Care Provider
PDSA	Plan/Do/Study/Act QI testing cycle
QI	Quality Improvement
SLC	Speech Language Consultant
WCHS	Women and Children’s Health Section
WIC	Supplemental Nutrition Program for Women, Infants and Children
UNHS	Universal Newborn Hearing Screening

## Abbreviations

Appt	Appointment
Dx	Diagnosis

## INTRODUCTION

Hearing loss is the most frequently occurring congenital condition, with a national incidence rate of 1.5 per 1000 births (2011 Centers for Disease Control and Prevention (CDC) Early Hearing Detection and Intervention (EHDI) Hearing Screening & Follow-up Survey). To identify children with congenital hearing loss and ensure that these children and their families receive timely, high quality services, the North Carolina General Assembly passed legislation in 1999 requiring that a hearing screening component be incorporated into the Department of Health and Human Services' Newborn Screening Program. The promulgated legislation stated, "The Program shall include, but shall not be limited to: For each newborn, provision of a physiological screening in each ear for the presence of permanent hearing loss." [SL2000, Ch.67, s.11.31, (a) (5)]. In 2000, when this legislation became effective, the EHDI Program was established within the Children and Youth Branch of the Division of Public Health.

North Carolina consistently exceeds the benchmark for completion of newborn hearing screening by one month of age. All medical facilities that provide birthing or inpatient neonatal services conduct universal newborn hearing screening. Since 2005, over 98% of all infants born in North Carolina have been screened.

Hearing screening is only the first, though very important, step in the Early Hearing Detection and Intervention process. Infants who do not pass newborn hearing screening need to have follow-up testing to determine if hearing loss is present and intervention needs to be started as quickly as possible to provide the best possible outcomes for the child. The EHDI Benchmarks for hearing screening and follow-up are known as the "1-3-6" plan – completion of screening by one month of age, diagnosis by three months of age, and early intervention by six months of age. For the benefits of universal newborn hearing screening to be fully realized, screening must be appropriately coordinated and linked with diagnostic and early intervention services and the child's medical home in a way that is family-centered and culturally competent.

The Healthy People Initiative and Maternal and Child Health Bureau (MCHB) national performance measures support the 1-3-6 Benchmarks and are at the core of the North Carolina EHDI (NC –EHDI) Program. Healthy People 2020 identified early detection of hearing loss as a significant preventable threat to people's health. The Healthy People 2020 goals include:

**ENT-VSL-1** Increase the proportion of newborns who are screened for hearing loss by no later than age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services no later than age 6 months

**ENT-VSL-1.1** Increase the proportion of newborns who are screened for hearing loss no later than age 1 month target: **90.2%**

**ENT-VSL-1.2** Increase the proportion of newborns who receive audiological evaluation no later than 3 months for infants who did not pass the hearing screening target: **72.6%**

**ENT-VSL-1.3** Increase the proportion of infants with confirmed hearing loss who are enrolled for intervention services no later than 6 months target: **55%**

Early identification, diagnosis and intervention are critical to language learning, school success and life-long achievement for persons born with hearing loss. Research has shown that children who are identified with permanent hearing loss early, who are either fitted with appropriate hearing aids or given cochlear implants, in conjunction with early intervention services from trained staff, are likely to progress at age-appropriate rates (Moeller, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998), and require few, if any, special education services when they enter school. Appropriate early intervention for all infants with confirmed permanent hearing loss should begin before six months of age (Joint Committee on Infant Hearing, 2007). Left unattended, consequences of permanent hearing loss can have long-term detrimental impact on all aspects of a child's development.

Fifteen key goals for an effective EHDI system have been identified (Yoshinaga-Itano, 2011). Those which will be addressed in this proposal include:

- Facilitate processes that increase the probability that families will follow up;
- Report follow-up immediately to state EHDI databases;
- Ensure timely contact after referral by knowledgeable early intervention providers;
- Ensure that the infant who is deaf or hard of hearing has audibility across the speech frequencies needed to learn spoken language;
- Ensure that families have peer support available as early as possible.

The numbers of infants lost to follow-up/lost to documentation or not reaching the three-month diagnostic goal or six-month intervention goal continue to be major concerns for all states. Our aim is clear – we are striving to reduce the number of infants born in North Carolina who are lost to follow-up or lost to documentation following a failed newborn hearing screen. Our ideas for changes that will result in improvement within the EHDI system will be implemented using Plan/Do/Study/Act (PDSA) cycles. North Carolina has developed a comprehensive data collection and management system, WCSWeb-Hearing Link which will assist us in the determination if our measures of improvement are successful in accomplishing what we expect them to accomplish. Through utilization of specific quality improvement methods, such as developing aim statements, designing change strategies, implementing PDSA cycles, evaluating results and spreading successful changes, significant improvement in the loss to follow-up/loss to documentation (LTF/D) rate nationwide has accrued.

North Carolina was privileged to not only participate in NICHQ in 2009, but to also participate in a quality improvement training program in conjunction with the North Carolina Center for Public Health Quality at North Carolina State University in 2011. The Center for Public Health Quality (CPHQ) is now a national resource for quality improvement among public health organizations. NC CPHQ collaborated with local health departments and the NC Division of Public Health (DPH) to develop groundbreaking quality improvement (QI) training and technical assistance programs. The EHDI Program was one of the first DPH programs to participate in a Learning Collaborative through NC CPHQ. Through the process, the team learned additional quality improvement techniques, such as Value Stream Mapping and Fishbone Diagrams. Today, CPHQ makes all of these programs available to public health organizations nationally and two members of the EHDI team remain actively involved as peer QI Advisors.

The NC-EHDI Program has been successful in many respects, but still faces significant challenges in reaching the 1-3-6 Benchmarks. The primary purpose of this grant application is to strengthen and sustain the EHDI system in North Carolina and achieve measurable improvement in the numbers of infants who receive appropriate and timely follow-up. The proposed activities of this project will expand upon previous successes and introduce new strategies for continued improvement utilizing proven quality improvement methodology. The aim for this grant is to reduce by 5% per year the percentage of children who are lost to follow-up/lost to documentation after not passing a newborn hearing screening.

Five goals aimed at strengthening the NC-EHDI system and increasing the number of infants and their families receiving timely, appropriate, high quality and culturally competent services have been identified. Three goals focus on maintaining or exceeding the current completion rate of the newborn hearing screening process by one month of age, increasing by 5% each year the rate of completed diagnosis by three months of age, and increasing by 3% each year the number of infants diagnosed with hearing loss who are enrolled in early intervention by six months of age. The remaining goals relate to providing education for appropriate community groups and stakeholders, and developing new or strengthening existing collaborative relationships with programs, agencies and individuals working in the interest of identifying and serving children with hearing loss and their families.

## **NEEDS ASSESSMENT**

In order to describe systems and system needs in North Carolina, it is helpful to begin with a description of the state geography and its population. North Carolina has a population of 9,535,483 based on the United States Census Bureau 2010 census, reflecting 18.5% growth since the 2000 census. The state's population growth has exceeded the national average for five consecutive decades. North Carolina covers 48,692 square miles and has an average population density of 196.1 persons per square mile. The state is comprised of 100 counties and three primary geographical regions. The Mountain, Piedmont, and Coastal Plain regions have uniquely different topographical and cultural characteristics. North Carolina also has three primary metropolitan areas – Charlotte, the Triad (Greensboro/High Point/Winston-Salem), and the Triangle (Raleigh/Durham/Chapel Hill). These three areas include 25% of the state's population, while occupying only 5% of the state's land mass, and all are located within the Piedmont region.

The combination of uneven population distribution, three unique geographical regions, and large land mass impacts many aspects of our health care systems, such as availability of providers, transportation to/from services, and economic viability of service sustainability in non-urban areas. There are 70 counties which are designated as Medically Underserved Areas (MUA) and an additional 24 counties which contain census tracts or minor census divisions which are designated MUA. Only six of the state's 100 counties are not designated MUA for any part of their county. Additionally, ten counties are designated as Primary Care Health Professional Shortage Areas (HPSA) with another 35 counties designated HPSA for special populations or only a portion the county.

The people of North Carolina speak a multitude of languages and come from varied cultural backgrounds. Census data from 2000 and 2010 reveal North Carolina had a 39.62% increase in

foreign born residents and a 32.5% increase in residents over the age of five who speak a language other than English in the home. Approximately 122 different languages are spoken by our residents. North Carolina has also seen a growing proportion of racial/ethnic minorities. The minority population accounts for 31.5% of the state's population, exceeding the national average of 27.6% and indicating 12.9% growth from 2000 to 2010. The proportion of children under five that are racial/ethnic minorities is consistent with that of the state's total population at 31.38%. For this age group, 16.7% are of Hispanic or Latino origin, compared to 8.4% of North Carolina's total population.

North Carolina is home to four military bases (Fort Bragg, Camp Lejeune, Marine Corps Air Station Cherry Point, and Seymour Johnson Air Force Base) and accounts for nearly 11% of the nation's military active duty personnel. There are two military hospitals, Womack Army Medical Center and the Naval Hospital at Camp Lejeune, both of which fully participate in our state newborn hearing screening program and they account for approximately 4% of live births annually. The transient nature of this population, deployment of active duty personnel, and hospitals run by two different branches of the service (army and navy) also impact systems.

North Carolina had 120,389 live births in 2011, which ranks eighth highest in the United States. Of these live births, 13% were pre-term (less than 37 weeks gestational age) and approximately 2,084 (1.7%) were very low birth weight (less than 1500 grams). Additionally, 41.4% of live births and 9.1% of low birth weight infants were born to minority mothers. Maternal education level was less than 12 years for 19% of these births. The 2011 incidence of teen births (mother's age 15-17 years) is 17 per 1000 births. For 2011-2012, 83% the parent(s) of children ages birth to three years reported they did not receive a new parent home visit.

The 2011 estimate of uninsured children under age 19 in North Carolina is 9.4%. In the same year, the percentage of children under age five living in poverty is 30%, compared to the 26% national average for children under age five and to the 16.1% of North Carolina's total population.

North Carolina's Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) currently has approximately 160 offices statewide. Average monthly participation by key populations related to this proposal for 2012 was as follows: 64,447 infants; 15,887 breastfeeding women; 18,535 postpartum women; and 27,789 pregnant women.

Legislation establishing the NC-EHDI Program was introduced in the North Carolina General Assembly in 1999. This legislation was formally adopted in July 2000 (G.S. 130A-125, SL2000 CH67 S11.31a5). Administrative rules governing newborn hearing screening and reporting became effective in August 2000 (10A NCAC 43F.1201-1204) and were updated in August 2004. These administrative rules include requirements for the reporting of all physiologic hearing screening completed for infants less than six months of age and of all diagnostic auditory evaluations and assessments for selection of amplification for infants less than twelve months of age. Results are required to be reported within five days of the appointment, including missed appointments. The majority of North Carolina birthing facilities meet the "reported within five days" reporting requirement, though we continue to have a few facilities and several audiology practices that do not meet this requirement.

Currently, all of North Carolina's 87 birthing/neonatal facilities offer initial newborn hearing screening services prior to infant discharge from the facility. Fifteen (17%) of these birthing facilities are located within the three primary metropolitan areas of the state and account for 40% of annual births. Preliminary data indicate 99.3% of infants born in North Carolina in 2012 were screened for the presence of permanent hearing loss, with 97.3% documented as being screened for hearing loss before one month of age. In North Carolina, infants who do not pass the inpatient screening are referred for follow-up outpatient re-screening, unless a direct referral for diagnostic evaluation is indicated due to high risk. Preliminary 2012 data indicate 914 infants did not pass the newborn hearing screening process, and 326 (36%) of these infants never received their recommended outpatient re-screen.

The availability and distribution of qualified pediatric audiologists in the state is a need specifically related to this grant proposal. Through self-report, there are 19 audiology practices that are able to provide infant diagnostic audiology services, with 12 of these located within the three primary metropolitan areas. The practice distribution by geographical region indicates 15 of the practices are located within the Piedmont region in the center of our state and two practices each are located in the Mountain and Coastal Plain regions.

The Coastal Plain region makes up nearly 45% of the total land mass in North Carolina. With only two pediatric audiology practices and such a large land mass, this region has significant needs related to distance travelled to obtain audiology services. Tele-audiology is a strategy being used in this part of the state and offers potential benefit for the Mountain region as well.

Preliminary data for infants born in 2012 indicate 164 (17.9%) infants who did not pass their final hearing screening were diagnosed with permanent hearing loss. Of the 340 infants who received a diagnosis of either normal hearing or permanent hearing loss, 21.5% were diagnosed with permanent hearing loss by three months of age. However, only 50% of the infants who needed follow-up testing completed their diagnostic evaluation by three months of age. There are 22 (2.4%) of the infants who did not pass their final hearing screening who are "in process", meaning they have been seen by an audiologist at least once, but have not yet received a confirmed diagnosis of permanent hearing loss or normal hearing.

WCSWeb is a web-based data tracking and surveillance system developed and utilized by both NC-EHDI and Sickle Cell programs within the North Carolina DPH. The EHDI Information System (EHDI-IS) part of this system is referred to as "Hearing Link". This system is a unique web-based tracking and surveillance system which allows for direct data entry and tracking by providers throughout North Carolina. Hearing Link currently includes direct data entry from birthing facilities, intervention providers, and audiologists for: (1) demographic information for each occurrent birth, (2) hearing screening results, (3) newborn metabolic screening specimen information, (4) diagnostic audiologic evaluation results, (5) amplification selection results, (6) early intervention referral and enrollment results, (7) information regarding follow-up appointments, and (8) EHDI program follow-up notes. All of this data is individually identifiable. Even though use of Hearing Link is voluntary at this time, 86 of the 87 birthing facilities, 214 audiologists, and representatives from three early intervention agencies in North Carolina have been trained to use the system. Additionally, several other medical providers such as local health departments and primary care practices have access to the system.

In November 2011, NC-EHDI began receiving individually identifiable data from early intervention service providers. Previously, we received only aggregate data from those providers. We have developed a coordinated referral process, which obtains a parent signature allowing release of information from NC-EHDI to all agencies that are available to serve children who are deaf or hard of hearing and their families, including children over the age of three years. This has allowed us to collaborate with Part C and the Department of Public Instruction (DPI) regarding reporting of individually identifiable data for intervention services to Hearing Link. Reporting protocol modification needs to continue in order to ensure routine and timely reporting of this data and reporting of child-specific intervention data for those infants enrolled in Part C for whom hearing loss is not the only or primary qualifying condition.

Of the 164 children born in 2012 who were diagnosed with permanent hearing loss, preliminary data indicate that 136 (82.9%) were enrolled in early intervention services. Additionally, 102 (62.2%) were enrolled before six months of age.

Previously, the Early Intervention for Children Who Are Deaf or Hard of Hearing (EIDHH) program was able to enroll children into intervention services provided by their program prior to enrollment in the North Carolina Infant Toddler Program (NCITP). EIDHH also could provide intervention services to children who were not enrolled in the NCITP. Procedural changes enacted during 2012 now require all children to be enrolled in the NCITP prior to receiving services from EIDHH. Education for families and audiologists to better understand this process has been initiated. However, the decrease in percentage of children enrolled in intervention before six months of age may be the result of this procedural change.

In June 2013, Hearing Link received the first birth certificate data file. This file included all infants born since January 1, 2011. Integration of the birth certificate data into Hearing Link will make data about infant race and ethnicity, as well as maternal age and education level, more readily available to the EHDI program. A bi-weekly data import process will be utilized.

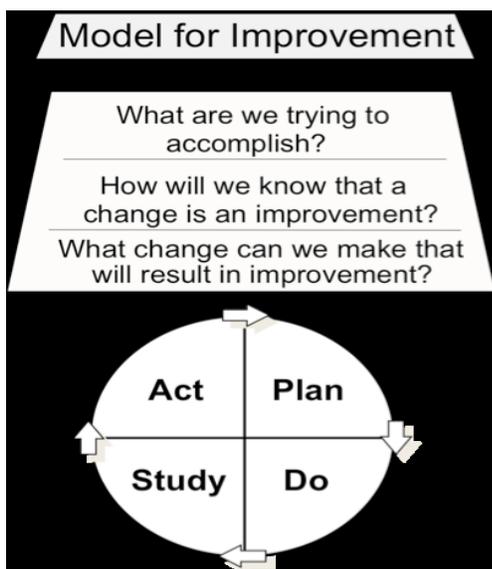
A weighted algorithm is used to reduce duplication of data at the time of data entry into Hearing Link, either by direct data entry or by electronic data transfer. The accuracy of the weighting scale will be evaluated on an on-going basis, to insure that we are not missing any infants or duplicating data.

Continuing challenges related to data reporting include: (1) under-reporting of re-screening and/or diagnostic evaluations for infants suspected to have a hearing loss, (2) under-reporting of amplification fitting for children with diagnosed hearing loss, (3) under-reporting of early intervention enrollment, (4) under-reporting of risk factors for late-onset or progressive hearing loss, and (5) under-reporting of discharge date for infants born in hospitals. The on-going analysis of data will be utilized in the continued development of future versions of Hearing Link and program evaluation.

Additional data reports related to facility/provider performance are being developed for use with hospitals, audiologists, and intervention providers as part of NC's EHDI Cooperative Agreement with the CDC. These reports will be utilized in conjunction with activities included in this grant proposal in efforts to increase timely and accurate data reporting.

## METHODOLOGY

The NC-EHDI Program will use the foundation of past accomplishments and the promise of strategies tested through quality improvement methodology to reduce loss to follow-up and develop a more effective and efficient EHDI system. The effective use of data is necessary to improve program performance. Through the collection and regular use of data, the EHDI program and its collaborators can identify methods to improve performance as well as document changes and challenges. Data collection and analysis allows for the identification of weaknesses within the system and areas needing improvement. The use of Continuous Quality Improvement (CQI) methods will result in enhancement and expansion of successful strategies to identify children with or at risk of hearing loss, as well as to improved outcomes for children.



The Model of Improvement that NC-EHDI has employed in the past incorporated identification of needs and design of quality improvement strategies based on small tests of change. PDSA cycles have been utilized to test, revise and spread change strategies as appropriate. Throughout the process, data has been used to determine the success of the strategies, the need for further testing of the change ideas and the success of spreading the change for sustainable improvement in the program. Stakeholders have been engaged in all aspects of the process from identification of need through examination of data to determine the success of the change strategies and of the subsequent spread. The same processes will be used to achieve project aims stated within this grant proposal.

NC-EHDI has successfully collaborated with many state agencies and community partners. The roles of those partners vary, but each stakeholder is actively involved in Program planning and providing ideas for quality improvement. EHDI is part of Title V in North Carolina. Title V funding is used in part to support program operating expenses and also contributes to the sustainability of the EHDI Program.

The Maternal, Infant and Early Childhood Home Visiting (MIECHV) Program is coordinated through the Health & Wellness Unit in the Children and Youth (C&Y Branch), allowing for close collaboration and strengthened family engagement. Information about the EHDI Program was provided to the MIECHV home visiting staff and they have been helpful in educating families about the need for follow-up from newborn hearing screening, thus helping reduce loss to follow-up. They have also increased awareness of the milestones of normal speech development. The regional consultants have assisted the MIECHV programs with hearing screening clinics to identify late-onset hearing loss in the population of children they serve.

Head Start Programs provide hearing screening for children and can assist the Program in reducing loss to follow-up and identification of late-onset or progressive hearing loss in children. NC-EHDI regional consultants collaborate with Head Start programs to provide training regarding hearing screening best practice and to provide mass hearing screening when needed.

Part C EI is coordinated in North Carolina through DPH. It is also housed in WCHS, which contributes to strong channels of communication and collaboration. The EI Program consists of 16 Children's Developmental Services Agencies (CDSAs) throughout the state, some of which are contractual service providers. They work with EHDI on the identification of unidentified or late on-set hearing loss within the population of children who have developmental delays.

The Department of Public Instruction (DPI) collaborates with NC-EHDI on issues relating to education for children of all ages that are deaf or hard of hearing. In 2012, the Early Intervention Program for Children Who Are Deaf or Hard of Hearing (EIDHH) was administratively placed under the DPI Office of Early Learning. EIDHH has always been a major EHDI collaborator. DPI contributes by service on the EHDI Advisory Committee and participation in the coordinated referral process. They provide contact information for all school districts. Public school audiologists have access to Hearing Link and report data when they identify late-onset or progressive hearing loss in a child. The EHDI Program Manager and the Parent Consultant sit on a statewide committee developing best practices for comprehensive education of children from birth through age 21 who are deaf/hard of hearing.

Collaboration has made expansion of EHDI-related services possible. CHACs recognized a need among the families for a way to organize all the materials they receive related to their children's hearing loss. This led to collaboration with parents to design a notebook that is now produced by EHDI and incorporates materials provided by EIDHH teachers who distribute the notebook to parents. The Teleaudiology Project is a collaborative effort with East Carolina University (ECU) Telemedicine Center and Department of Communication Disorders. It provides services in the rural medically underserved eastern counties of the State. Through collaboration with Robeson Healthcare Corporation, teleaudiology expanded into another medically underserved area with a high Native American population which previously had not had any telemedicine services. Future collaboration with the new North Carolina TelePsychiatry Program is expected to result in additional teleaudiology sites within the current service area as well as expansion into counties in the western part of the state, which also have great need among a largely Native American population.

Collaborative efforts would not be complete without input from the wide variety of stakeholders in the EHDI process. The EHDI Advisory Committee is an active group of stakeholders that examines needs and suggests solutions through quality improvement implementation, as well as long-range planning. It includes representation from most of the entities involved in the EHDI process, families, hospitals, the NC School for the Deaf, the NC Division of Services for the Deaf and Hard of Hearing, audiologists, EHDI Chapter Champions and university educators involved in the training of speech language pathologists and audiologists.

Since 2001, the EHDI Advisory Committee has met quarterly to provide leadership and support for NC-EHDI. The input and feedback provided by this broad spectrum of stakeholders (see Attachment #6) has provided guidance for North Carolina's EHDI Program. This active group, in conjunction with regional staff, has identified unique needs of target populations within the state and suggested possible strategies to meet those needs. The EHDI Advisory Committee continuously evaluates data from the CDC EHDI Hearing Screening & Follow-up Survey and

Hearing Link. During the April 2013 meeting, the Advisory Committee agreed to the following goals for 2013 – 2014:

- **To reduce delays from screening to diagnosis.** This goal was prompted by examination of the NC CDC data compared to other states. Issues identified included challenges of time and travel for many families to reach a qualified diagnostic site, and loss to follow-up/loss to documentation.
- **To begin establishing minimum standards for diagnostic audiology facilities.** The Massachusetts statute and guidelines regarding diagnostic audiology practices will be reviewed. The Advisory Committee would like to develop a similar set of standards for NC diagnostic practices.
- **To oversee the implementation and monitoring of EHDI-PALS:** EHDI-PALS (Pediatric Audiological Links to Service) is a web-based tool for identifying pediatric audiology practices. It is hosted by a task force convened by CDC, and NC was one of the states that piloted the tool. It is important that the information provided on EHDI-PALS is accurate, updated and maintained, which the Advisory Committee will monitor.

With guidance from the EHDI Advisory Committee, the NC EHDI program will reduce the number of babies lost to follow-up by employing proven quality improvement methodology to make and sustain small, tested changes throughout the EHDI system. A team of stakeholders will comprise the state QI team. The team will guide the quality improvement strategies supported by this grant, ensuring that improvement proposals are realistic and successfully executed, and that changes leading to improvement are spread throughout the EHDI system. The QI team will be active in providing ideas for PDSAs and in evaluating the effectiveness of the improvement strategies undertaken. The team consists of the following stakeholders:

- two parents of children identified with hearing loss,
- one EHDI Chapter Champion,
- the NC MIECHV Data & QI Coordinator,
- an Advisory Committee member and hospital EHDI coordinator who participated on the NICHQ QI team, and
- a lead teacher from EIDHH,
- A pediatric audiologist to participate on the QI team has not yet been identified.

EHDI program staff members on the QI team are:

- the Program Manager,
- the Development and Evaluation Manager,
- the Follow-up Coordinator,
- the Project Coordinator for the Health Resources and Services Administration (HRSA) grant,
- one of the Child Health Audiology Consultants, and
- one of the Child Health Speech Language Consultants.

The QI team has been convened for its first meeting to discuss the goals of the grant and to identify and prioritize possible change strategies leading to program improvement. The team

plans to meet monthly by conference call with two meetings each year in person if travel permits.

Smaller teams will be established at the local level. The Local Quality Improvement (LQI) teams will be comprised of local EHDI personnel and stakeholders who are familiar with the characteristics of the population they serve, as well as the services and resources available in the area. They will meet frequently to plan and assess progress on individual PDSAs and to evaluate their effectiveness. One LQI team has met to design an improvement initiative. This team consists of the regional CHAC, the regional SLC, a diagnosing audiologist and the scheduling coordinator at a diagnostic center in the eastern part of the state. This LQI team will continue to meet throughout the PDSA process and will be active in the spread of the initiative if it proves to be effective.

The primary aim of the grant is reduction of loss to follow-up /loss to documentation at each step in the EHDI process. Five goals aimed at strengthening the North Carolina EHDI system have been identified. They will ensure that the services infants and their families receive are timely, appropriate, high quality and culturally competent. These goals focus on:

- completion of the newborn hearing screening process by one month of age,
- completed diagnosis by three months of age,
- enrollment in early intervention by six months of age,
- education of appropriate populations and stakeholders, and
- collaboration among agencies and individuals working in the interest of identifying and serving children with hearing loss and their families.

Within each of these goals there are objectives that are measurable and serve to guide the activities and quality improvement change ideas that will optimize outcomes within the EHDI system. In addition to the PDSAs being developed, the EHDI Program will continue with those activities that have proven to be successful through continuous quality improvement (CQI) efforts. The goals and objectives will be described in detail in the Work Plan section of this proposal.

The goals of this proposal will be met through collaborative efforts between EHDI stakeholders and EHDI program staff. NC-EHDI is fortunate to have staff supported through HRSA and CDC funding, as well as those supported by a combination of funding from the state and Federal Financial Participation (FFP) from Title XIX Medical Assistance Program (Medicaid). Having sufficient staffing allows for a spectrum of services not afforded all EHDI programs. Education and support is available to families, hospitals, pediatric audiologists, medical homes and other key stakeholders, and quality improvement will be used to enhance and expand those services and others aimed at reducing the loss to follow-up within the NC EHDI system.

With recent inclusion of birth certificate information into Hearing Link records, we will be able to determine trends within different sub-populations throughout the state and target strategies to meet unique culturally diverse needs. Though Hearing Link has provided valuable individually identifiable real-time data about hearing screening and follow-up, the system has not had enough information to identify distinct needs within differing demographic groups. Some of the strategies developed by the QI team were designed to meet needs within specific populations, such as translation of the NC newborn hearing screening brochure into Japanese for the

significant population of military wives who are of Japanese heritage (Objective 1.2 Activity) and trying to reach families by email or text as a means of reaching more of the younger parents (Objective 1.2 Change Idea). Additional factors that are expected to impact families' fulfillment of newborn hearing screening follow-up include: maternal age and educational level, parental race and ethnicity, gestational age and birth weight.

As strategies for specific populations are developed, staff will be provided with training to address the unique characteristics within that population. Staff training has been available through a variety of sources, including provision by the C&Y Branch Coordinator for Minority and Special Population Needs. Outreach to families and individuals within the community who can increase cultural understanding and help identify possible approaches and solutions will be done. Additional training will be provided to address the distinct traditions, habits and characteristics of the families within each group. With increased understanding, specific strategies will be developed to address identified needs. When appropriate the strategies may be spread to other groups throughout the state.

With local involvement in the planning and implementation of quality improvement strategies, we foresee that effective changes implemented as the result of this project will be sustained. Improved outcomes for the target populations resulting from new or refined strategies will lead to permanent adoption of successful changes. Interventions and services developed will be incorporated into materials about best practices for hospitals, pediatric audiologists, medical homes and other stakeholders in the EHDI process. Sustainability of changes within the EHDI program is easily accomplished through adoption of new procedures. Quality improvement methodology, including using data for the identification of needs and evaluation of change strategies, implementation of small tests of change, spread of successful strategies and stakeholder involvement throughout the process, will be maintained beyond the period of the grant as staff and stakeholders recognize the improvement that results from this approach.

## **WORK PLAN**

This work plan will provide the background for each of the objectives and proposed changes being set forth in this grant. The means of measurement of success for the quality improvement strategies and anticipated spread of successful strategies will be provided. See Attachment 1 for the timeline for each of the proposed activities and the responsible staff. Additional change ideas were considered by the QI team but determined to be dependent upon other priority change ideas that needed to be tested first.

***Grant Aim: To reduce by 5% per year the percentage of children who are loss to follow-up/documentation (LTF/D) after not passing a newborn hearing screening.***

**System Goal 1: Newborn hearing screening will be completed on all infants born in NC hospitals prior to discharge, and for those infants needing a follow-up screening and those born at home, screening will be completed by 1 month of age.**

**Objective 1:** Maintain the percentage of 97.5 for infants who were screened by 1 month of age. Healthy People 2020 goal is 90.2% (ENT-VSL-1)

The overall screening rate for infants born in North Carolina is well over the goal set in Healthy People 2020. Of all babies born in NC birthing facilities 98.8% are screened during their birth admission. Based on the success with this objective, the QI team decided that this aspect of the EHDI program did not require quality improvement attention at this time. However, two key activities related to working with midwives should be continued. A small percentage of NC births (.5%) occur outside of birthing facilities. Though this is a small percentage of the total number of births, we continue to work with midwives to ensure that many of these babies receive a hearing screen. In order to maintain our screening rate of 57% within this small population, we will continue the following activities: (1) meet with midwifery practices to determine procedures for assuring babies in their care have a newborn hearing screening, and (2) provide on-site training and technical assistance to midwifery practices conducting newborn hearing screening.

**Objective 1.2:** By March 31, 2017, reduce the percentage LTF/D by 9% for those babies needing rescreening.

North Carolina uses an inpatient screen/ outpatient rescreen process. The most recent data available (2011) indicates that of 877 babies who did not pass the inpatient screen and were referred for a rescreen, there were 227 (25.9%) not rescreened. These infants account for a significant proportion of the total LTF/D in the state. The QI team discussed several possible strategies to address the need for improvement in this program area. It was determined that in addition to three new change ideas, it was important to continue many of the activities currently in place.

**Objective 1.2a:** By March 31, 2017, increase by 10% the percentage of infants that complete the needed rescreen at 1 month for of age.

Of those infants needing a rescreen in 2011, 62.4% were completed by one month of age. It is important to address the timeliness of completion of the rescreen not only because of the JCIH goal of completion of hearing screening by one month of age, but also because of the identified need in North Carolina to increase the number of diagnostic evaluations completed by three months of age. A delay in rescreening will often result in a subsequent delay in meeting the 3 month diagnostic goal. This objective is also integral to Objective 1.2, thus the activities and change ideas for the two objectives will be the same. The aim is two-fold: to1) increase the rescreens completed by one month of age, and 2) decrease the number of children needing rescreens who are LTF/D.

**QI Change #1 for Objectives 1.2 and 1.2a:** Develop a system to utilize faxing as an effective means of communication with medical homes regarding newborn hearing screening results and needed follow-up.

**BACKGROUND:** During the NICHQ Collaborative, use of faxes to notify PCPs of failed hearing screening results was tested. Faxed results were sent from the two hospitals that partnered with the EHDI program for the collaborative. Both hospitals have continued using faxes after completion of our NICHQ testing. One of the strategies tested and found to be effective was identification of a specific person (single point of contact) to receive and handle the fax in the medical home office.

PLAN: (1) Develop a fax form designed to capture the attention of the medical home staff and emphasize the need for follow-up. (2) Identify the tracking staff member to test this method of communication with medical homes. (3) Identify three hospitals with which the faxing strategy can be used for communication with the medical homes (4) Use data available in Hearing Link to determine the baseline on the percentage of rescreens completed by 1 month of age at the hospitals in order to determine the impact of the strategy.

DO: (1) Faxes will be sent to the medical homes for babies born in the test hospitals after the first missed appointment for an outpatient re-screening.

STUDY: Questions to ask:

- Was the fax received by the medical home and made available as part of the child's medical record?
- Are revisions needed in the fax form?
- Does the fax need to go to a specific person? If so, to whom (the doctor, a nurse, the practice manager) should it be addressed?
- After three months of using this process, is there an increase in the percentage of rescreens completed by one month of age? Is there a decrease in loss to follow up? Is there enough data to determine this?

ACT: Planning for this change strategy and completion of all testing is anticipated to take about nine months. If the process has proven to be successful, the spread will be rapid because this is an internal process which can easily be incorporated into tracking procedures.

**QI Change #2 for Objectives 1.2 and 1.2a:** Collaborate with the Women Infant and Children (WIC) program to have questions about completion and results of newborn hearing screening asked at the first WIC appointment after the birth of a baby.

BACKGROUND: Though the EHDI program regularly collaborates with Local Health Departments to locate children who may become LTF/D, specific linkage with WIC programs has not been attempted. Because WIC programs provide infant formula and food vouchers, families that qualify are likely to come for their appointments. The QI team believes direct collaboration with WIC programs may be a successful means of reaching families that has not been previously utilized. A PDSA to explore the possibility of having WIC programs work with the EHDI program and to test the effectiveness of their involvement was developed by the QI team. The anticipated result is that fewer children needing a rescreen will be LTF/D. Whether or not this will impact the age of the infant at the time of the rescreen will be learned through the PDSA process.

PLAN: (1) Identify one WIC office to work with the EHDI program and collect baseline data for the population that is served by that WIC office. (2) Develop one or more questions about the newborn hearing screening results that WIC staff will ask during the first appointment following the infant's birth.

DO: Have WIC staff ask the question(s) developed in the Plan phase for a three month period of time.

STUDY: Questions to ask:

- Were any problems encountered?
- What went well?
- Do the questions need to be changed?
- Did the WIC staff remember to ask the questions of all appropriate mothers?
- Would it be helpful to give the mothers a number so they can call to follow-up on obtaining a rescreen for their baby? Does the WIC staff feel this would be helpful for the parent?
- Can WIC staff give information to EHDI staff without the mother's consent?

ACT: The need for further planning and testing is anticipated to answer the questions above. Assuming the desired outcome occurs, the strategy will be spread to 160 WIC sites throughout the state. To accompany the spread and make the system efficient, WIC staff may need to be trained to enter the answers they receive into Hearing Link. Full implementation of this change initiative, if successful, is expected to take the full three years of the grant.

**QI Change #3 for Objectives 1.2 and 1.2a:** Have screeners and tracking staff ask for and use the best means of contact (phone, email, text, etc.) identified by the family when a baby does not pass the initial newborn hearing screening, and enter the information into Hearing Link.

BACKGROUND: The QI team expressed an interest in modernizing our modes of communication with families. The belief is that young mothers are more likely to respond to an email or text rather than to a phone call. This change idea will focus on identifying the best way to communicate with each individual family whose child has not passed the initial hearing screen, rather than relying primarily on phone calls (often leaving messages), or sending letters. Using the PDSA model, we plan to explore the feasibility of obtaining individual preferences for means of communication with a family whose child needs follow-up. We will then analyze the impact this has on the LTF/D rate at the rescreen step or the age of completion of the rescreen.

PLAN: (1) Design a script asking for the best way to contact a family whose baby has not passed the hearing screen. (2) Develop a protocol for entering this additional information into Hearing Link. (3) Identify the tracking staff member who will work with this new system to follow-up with families. (4) Identify two hospitals willing to test this PDSA. (5) Use data available in Hearing Link to determine the baseline percentage of rescreens completed by 1 month of age and the rescreen LTF/D rate at the participating hospitals.

DO: (1) Train all involved staff at the hospital to follow the new script and to enter the new information into Hearing Link. (2) Have tracking staff use the best means of contact identified by families from the two hospitals.

STUDY: Questions to ask:

- What went well?

- Was the new script helpful? Does it need revisions?
- Are more families being reached?
- Are more families following up with the needed rescreen?

ACT: Determination will be made on whether to adapt, adopt or abandon the change. If adaptations are needed, further PDSA cycles will be used to refine the procedure. Spread of this change idea will involve training of all hospital screeners and is anticipated to take about six months.

**Continuing Activities for Objectives 1.2 and 1.2a:**

- Provide Newborn Hearing Screening Program training and technical assistance to all birthing facilities, including rescreen program development and refinement.
- Identify and distribute new resources for hospital “tool kits.”
- Provide NC newborn hearing screening brochures and hearing healthcare maps to all birthing facilities.
- Develop program plans annually with birthing facilities and hospital visits at least twice a year.
- Coordinate centralized tracking of infants.
- Translation of the NC newborn hearing screening brochure (Japanese translation requested)
- Explore different methods of alerting primary care providers to the need of follow-up screening or testing via electronic medical records.

**Additional Change Idea** (to be tested after or with Change Idea #3 implementation)

- Have screeners assist parents in setting up reminders on their cell phones about the time for a follow-up screening appointment.

**System Goal 2: All infants who “refer” on their final newborn hearing screening and neonatal intensive care infants who fail their initial screening will receive an audiological diagnosis by three months of age. Healthy People 2020 goal is 72.6% (ENT-VSL-2)**

**Objective 2.1:** By March 31, 2017, reduce by 15% the percentage of infants LTF/D at the diagnostic step.

The LTF/D rate for North Carolina for 2011 was 34.3%, slightly lower than the national average of 35.3%. Of the 877 babies who did not pass their final newborn hearing screen, there were 70 families who were contacted but unresponsive; 209 families that NC-EHDI was unable to contact due to faulty or missing contact information; and, 22 families where the outcome of attempts to contact are unknown. These babies may have been lost at either the rescreen step or the diagnostic step in the newborn hearing screening and follow-up process. The QI team decided that quality improvement strategies for reducing LTF/D at this step needed to be combined with strategies to meet the need to increase the percentage of babies who complete diagnosis by three months of age.

**Objective 2.1a:** By March 31, 2017, increase by 15% the percentage of infants that complete the needed diagnostic evaluation by three months of age.

Though our LTF/D rate is at the national average for infants needing a diagnosis, the age at which the babies are completing the diagnosis is later than we would like. In 2011, 464 of the babies born completed a diagnostic evaluation. Of those babies, 47.4% (220) completed the diagnostic process by three months of age; 25% (116) completed the diagnosis between three and six months of age; 27% (128) completed the diagnostic evaluation when they were over six months of age. We will implement quality improvement strategies that will increase the rate of completion to be more consistent with the Healthy People 2020 and JCIH benchmark of completion of diagnosis by three months of age.

**QI Change #1 for Objectives 2.1 and 2.1a:** When a child does not pass their hearing screen or rescreen, send a letter to the medical home about the child needing a diagnostic evaluation, including information about measures that will help keep the infant asleep during the procedure. When a letter is sent to the family, include the same information.

**BACKGROUND:** During an Advisory Committee meeting early in 2013, there was discussion of the need to improve the percentage of infants who complete the diagnostic evaluation by three months of age. For each child who needs a diagnostic evaluation the SLC calls and sends a letter to the child's medical home. After hearing that, one of the pediatric audiologists on the Committee suggested that the letter include information about measures to help keep the infant asleep during the procedure with a request that the PCP help educate the family. Because so many of the children live more than an hour's drive away and fall asleep during the trip, they are awake and unable to complete the testing when they reach the diagnostic facility. This problem was also noted by one of the CHACs in reviewing the 2011 data for her region. The data illustrated that the further a baby lived from the diagnosing facility, the more likely the need for second appointment to complete the diagnostic process.

**PLAN:** (1) Work with the audiologist who recognized this need. (2) Develop a means of collecting data on the distance a family travels and the length of time/number of visits it takes to complete diagnosis. (3) Collect data. (4) Revise data collection form if needed. (4) Develop information to go into PCP letter.

**DO:** (1) Add additional information into letter being sent to physicians for five babies.

**STUDY:** Questions to ask:

- Did the change in the PCP letter result in a greater number of babies completing the diagnostic evaluation in one visit?
- Does the letter need revisions? More information? More explanation?
- Would it help if the parent letter included a short explanation for parents about the need for their baby to be asleep for the testing and helpful hints to accomplish this?

**ACT:** Much of the planning for this PDSA has been completed. The baseline data needs to be collected. When the new, expanded letter(s) have been tested and revised, the spread of the change strategy can occur quickly. The letter is an internal process for the EHDI program. If successful, both the letter to the medical home and to the parents can be changed. Statewide implementation of this strategy can begin immediately.

**QI Change #2 for Objectives 2.1 and 2.1a:** When a letter is sent to the family about their child needing a diagnostic evaluation, note in the letter that the same information is being provided to their medical home.

**BACKGROUND:** Diagnostic appointments that are missed often lead to a child being diagnosed after three months of age. Appointments for which the family is a no show are often associated with children who in the end are LTF/D. During a recent conference call meeting with SLCs who provide support to the families of children needing diagnostic evaluations, one of the SLCs said that she wondered if a statement that the child's PCP was receiving the same information as was being sent to the family would help decrease the number of times a family missed or no showed for an appointment. She will test a change in the letter she sends to families based on this change idea.

**PLAN:** (1) Identify the county where this change test will occur (Accomplished). (2) Collect data on the number of missed appointments and no shows in that county per family. (3) Determine exactly what information needs to go into the letter to the family and to the medical home.

**DO:** (1) Add additional information into the letters being sent families for five babies. (2) Send a copy of the parent letters to the medical homes.

**STUDY:** Questions to ask:

- Was there a change in the number of missed or no show appointments? Does more testing of the letter need to be done?
- Does the letter need revisions? More information? Different information?

**ACT:** Much of the planning for this PDSA has been completed. The baseline data needs to be collected. When the new, expanded letter and copying it to the PCP have been tested and the system revised as needed, the spread of this change strategy can occur quickly. The letters are an internal process for the EHDI program. The predicted outcome is that the addition to the letter to the parents and a copy of that letter to the physician will result in fewer babies LTF/D due to no shows that increase in the number of babies diagnosed by three months of age. Upon completion of the PDSA cycle to refine the process, both the letter to the parents and the letter to the medical homes can be changed and implementation statewide can begin immediately.

**QI Change #3 for Objectives 2.1 and 2.1a:** When a letter is sent to the family about their infant needing a diagnostic evaluation, include the EHDI Parent Consultant's contact information as a parent-to-parent resource.

**BACKGROUND:** Members of the Advisory Committee have questioned whether parent support occurring earlier in the EHDI process could help reduce our LTF/D rate. At this time, the Parent Consultant is expanding our support for parents after a diagnosis of hearing loss has occurred.

However whether or not it would be helpful for some parents to talk to another parent who has been through what they are facing and who can offer encouragement for timely completion of the audiological evaluation and a positive outcome regardless of the diagnostic results, has not been determined. This PDSA will explore the idea that earlier support from another parent will lead to a greater rate of completion of the diagnostic process within three months of age.

PLAN: (1) Determine how families will be notified of possible assistance from the Parent Consultant (Information in letter? Business card attached to letter? Information added to Hearing Healthcare Map? Other?). (2) Determine how to provide families this service (Email to schedule call with Parent Consultant? Toll-free number? Can the 800 number for the EHDI program be forwarded to Parent Consultant's cell phone?) (3) Determine which SLCs will send the Parent Consultant contact information.

DO: (1) SLCs send Parent Consultant contact information to 50 parents. (3) SLCs will include information about contact information in their tracking entries.

STUDY: Questions to ask:

- Did any parents contact the Parent Consultant?
- Should there be further testing of this method of providing the information? Should another method of providing the information be explored?
- Did only parents from a certain area/age group/socio-economic demographic contact the Parent Consultant?

ACT: As this will be a completely new initiative without baseline data for comparison, this change strategy may require additional testing and more time to determine if it is valid and should be spread. Once/if a method of providing contact information is determined to be effective, the spread will be fairly rapid. Again this will require a change in procedures internal to the EHDI program that can readily be achieved.

#### **Continuing Activities for Objectives 1.2 and 1.2a:**

- Maintain and distribute the list of pediatric audiologists able to provide diagnostic evaluation for infants.
- Provide family support from a failed rescreen through completion of diagnostic appointment(s).
- Notify the primary care provider when a child fails the rescreen.
- Provide training, technical assistance, education and resources to diagnosing pediatric audiologists.
- Provide Teleaudiology Services (rescreen and audiological evaluations) for children born in 36 rural NC counties.

#### **Additional Change Ideas** (to be tested later)

- When an infant has fluid at the time of the diagnostic evaluation and is referred to an Ear, Nose and Throat doctor, send the parent information about completing the diagnostic process after the fluid has been resolved.
- Have hospitals with a LTF/D rate of over 5% require their screeners to complete the newborn hearing screening curriculum (<http://www.infantheating.org/nhstc/index.html> )

**Objective 2.2:** By March 31, 2017, increase the number of Teleaudiology appointments to 28 per year.

The Teleaudiology Project serves a large area that is sparsely populated. Utilization of the service has not been as great as expected, with an average of 12 appointments per year. One of the reasons for the low utilization is that the family may have the diagnostic evaluation done at the facility that is following the child for other problems. Other factors may be related to family habitual patterns of where to go for medical care. With expansion of telemedicine services in the rural parts of the state, more sites will be available to provide this service. We will implement quality improvement strategies to increase utilization while we are working to increase the number of sites available.

**QI Change #1 for Objectives 2.2:** Following a failed rescreen, send Teleaudiology Program information to the primary care provider with information that the child needs a diagnostic evaluation.

**BACKGROUND:** During a recent meeting of the planning committee for the Teleaudiology Project, including EHDI staff, the Director of the ECU Telemedicine Center and the diagnostic audiologist from ECU, it was determined that one of the first strategies that needs to be explored to improve utilization of Teleaudiology services is to provide information to physicians in the service area about the availability of the service. Informational letters have been sent to all medical homes in the region. The QI team felt that sending a letter to the medical home at the time of referral for rescreen or diagnostic evaluation might increase the utilization of these services.

**PLAN:** (1) Develop letter to be sent to the medical home when a family lives in the service area, explaining the advantages of Teleaudiology. (2) Develop sets of questions to ask the family if they decide to use Teleaudiology/ not to use Teleaudiology.

**DO:** (1) Send the letter to the medical homes of the first six families living in the service area whose child qualifies for Teleaudiology services. (2) Ask each of the families the appropriate set of questions, based on whether or not they utilized the service. (3) Develop tracking sheets to be used to collect data needed to determine the success of this PDSA.

**STUDY:** Questions to ask:

- Determine the number of families whose physicians received a letter about the service.
- Determine if the physician talked to the family about Teleaudiology.
- Determine if the physician referred the family to the Teleaudiology Project.
- Determine if the family then used Teleaudiology.
- Should there be further testing of this method of providing the information?
- Should another method of providing the information be explored, such as calling the medical home to suggest using the Teleaudiology services?

**ACT:** The predicted outcome is that more infants will be referred for Teleaudiology services if the child's medical home is made aware of the service at the time the infant is in need. The best

method to accomplish this will be determined through the PDSA cycles. Spread will be implemented by the EHDI staff member providing support to families of infants that need follow-up from newborn hearing screening living in respective Teleaudiology service areas.

**Continuing Activities for Objective 2.2:**

- Provide Teleaudiology Services (rescreen and audiological evaluations) for children born in rural NC counties.
- Collaborate with the NC TelePsychiatry Program for development of new Teleaudiology sites.

**System Goal 3: All infants who are found to have permanent hearing loss will receive amplification, if recommended, and begin receiving early intervention services by 6 months of age. Healthy People 2020 goal is 55% (ENT-VSL-3)**

**Objective 3.1:** By March 31, 2017, for infants diagnosed with hearing loss, reduce the percentage LTF/D by 3%.

The overall rate of infants born in North Carolina in 2011 who were diagnosed with hearing loss and received intervention was 74.4%. Until August 2012, children with hearing loss could enroll directly in EIDHH. A recent change in the system requires that children be enrolled in Part C Early Intervention prior to enrollment in EIDHH. Based on preliminary subjective data, the EIDHH staff report a decrease in the number of children enrolled in their program. This concern will be addressed with Objective 3.1a which addresses the age of enrollment in early intervention.

**Objective 3.1a:** By March 31, 2017, for infants diagnosed with hearing loss, increase by 6% the percentage enrolled in early intervention by six months of age.

Despite the fact that less than half of the children needing an audiological evaluation receive one by three months of age, 64.8% of all children identified with hearing loss were enrolled in early intervention prior to six months of age. This percentage exceeds the Healthy People 2020 goal. However, there is room for improvement that the QI team decided to address in conjunction with Objective 3.1.

**QI Change #1 for Objectives 3.1 and 3.1a:** Call the family within two weeks of their child’s diagnosis and explain the value of early intervention for a child with hearing loss.

**BACKGROUND:** The EHDI program has relied on the diligence and friendly persuasiveness of the EIDHH staff to ensure that children were enrolled in appropriate early intervention. The EIDHH staff has educated parents about the value of their services regardless of the type or severity of the child’s hearing loss and the majority of parents decided to enroll. With recent changes, EIDHH is unable to contact a family until the child is enrolled in Part C early intervention. Current practice is calls for CHACs to verify that referrals have been made when they become aware of a child who is diagnosed with hearing loss. This process may take a matter of weeks between sending emails or leaving phone messages and waiting for replies. As a means of improving or at least maintaining the current high rate of enrollment in EIDHH,

members of the QI team suggested that the CHACs call the parents within two weeks of diagnosis to explain the value of EIDHH and the process for enrollment.

PLAN: (1) Determine which CHAC will work on this quality improvement activity and which counties she will use for the PDSA cycles. (2) Develop a list of topics the CHAC will discuss with parents. (3) Determine how the CHAC will ensure that she is tracking and calling families within two weeks of diagnosis. (4) Determine how data will be collected.

DO: (1) Have CHAC call all families of newly diagnosed children in designated counties within two weeks of diagnosis. (2) Have CHAC track the number of calls she makes to each family, the number of families she reaches, the number of families who return her calls, the topics covered and receptiveness of the family.

STUDY: Questions to ask:

- Determine the number of families reached by phone.
- Determine the number of families who enrolled in EIDHH following the phone call from the CHAC.
- Determine if different information is needed by the families.
- Determine if the families were aware of the information before it was provided by the CHAC.
- Should there be further testing of this method of providing the information? Should another method of providing the information be explored?

ACT: The expected outcome is that with a phone call explaining the value of EIDHH and encouraging participation will reduce the recent decline in EIDHH enrollment. Spread will occur first for the CHAC involved in the PDSA. If the trend continues as expected, she will make calls to families in all the counties she serves. If this proves successful for all of the counties in her region, the other CHACs will adopt this practice and the spread will occur throughout the state.

**QI Change #2 for Objectives 3.1 and 3.1a:** Provide access to the Parent Phone Tree by including business cards with the Parent Consultant's contact information with other materials being sent to the family following their child's diagnosis.

**BACKGROUND:** Parents of children with hearing loss have been trained to talk with parents of newly diagnosed children. NC-EHDI calls this the Parent Phone Tree. The QI team felt this group of parents would be an excellent source of information about EIDHH for parents who might be undecided about enrolling their child in the specialized early intervention program. The Parent Consultant's contact information will be given to parents along with other materials being sent following a child's diagnosis. She will refer parents to appropriate Phone Tree Parents when they contact her. By providing some additional information to the Phone Tree parents about the recent changes in EIDHH enrollment and with a more systematized means of ensuring that parents of newly diagnosed children receive information about the Parent Phone Tree, it is expected that more parents will choose to enroll their children in EIDHH.

PLAN: (1) Determine which counties will be receiving the contact information for the Parent Consultant. (2) Develop a business card for the Parent Consultant. (3) Determine how the Parent Consultant will track families that received information about her services from the business card. (4) Determine how data will be collected. (5) Provide information to the Phone Tree Parents on the changes in EIDHH and ways they might support a parent to enroll in EIDHH though the family may not feel the need to have all the Part C services.

DO: (1) Have the CHAC include the Parent Consultant's business card when information is sent out to families of newly diagnosed children in the selected counties. (2) Parent Consultant will track calls received from families who receive her business card with other information following the diagnosis. (3) Parent Consultant will provide contact information for a trained Parent Phone Tree parent who understands the new EIDHH enrollment procedures and can explain the value of EIDHH to the family. (4) Data will be kept on the number of families that enroll in EIDHH after talking with a Phone Tree Parent.

STUDY: Questions to ask:

- Determine the number of families who call or email the Parent Consultant.
- Determine the number of families who enrolled in EIDHH following contact with a Phone Tree Parent.
- Determine if different information is needed by the families.
- Determine if the families were aware of the information before it was provided by the Phone Tree Parent.
- Should there be further testing of this method of providing the information? Should another method of providing the information be explored?
- Is this a good way to get families to utilize the Parent Phone Tree even if it does not impact the number of families enrolling in EIDHH?

ACT: The predicted outcomes are that more parents will start using the Parent Phone Tree and that more families will choose to enroll their children in EIDHH as the result of talking with these Phone Tree Parents. This PDSA will probably take several cycles to determine the most effective way to get information to parents of newly diagnosed children and to determine if contact with Phone Tree Parents impacts the enrollment in EIDHH. The testing of this change strategy is expected to take several months. Spread will involve ensuring that all Phone Tree Parents are educated about changes in the early intervention system. This can happen simultaneously with the PDSA cycles, since this is information they need to know. If the strategy is proven successful, the spread will involve the CHACs sending the Parent Consultant business card with other materials to families which could be accomplished rapidly.

**Continuing Activities for Objectives 3.1 and 3.1a:**

- Collaborate with early intervention programs including Children Development Service Agencies (Part C) across the state, EIDHH and BEGINNINGS for Parents of Children who are Deaf or Hard of Hearing.
- Conduct trainings for Part C service providers about services for children with hearing loss, including EHDI and EIDHH
- Provide technical assistance to diagnosing audiologists on the effective use of North Carolina's form for intervention, Permission for Referral

- Distribute information to dispensing audiologists on the system of ensuring amplification for every child up to age 3 years.
- Provide training to audiologists on the use of the Hearing Link to document hearing aid information.
- Provide family support and education about the need for early intervention when a child has been identified with hearing loss.

Additional Change Idea (to be tested later):

- Scripting for diagnostic audiologists about the importance of and route to get in to EIDHH

**System Goal 4: Targeted education about newborn hearing screening and means of reducing loss to follow-up will be provided to appropriate populations.**

**Objective 4.1:** Provide educational opportunities and materials for 200 individuals or stakeholder groups each year of the grant.

EHDI regional speech and audiology consultants regularly provide targeted education across the State about newborn hearing screening, the importance of timely follow-up if a child does that pass the inpatient hearing screen and other related topics. Educational presentations and/or materials are offered to hospital personnel, Local Health Departments, Head Start programs, home visiting programs, medical homes, CDSAs, pediatric audiology providers, speech language pathologists, school systems, prenatal care classes and other community agencies. These educational opportunities increase the visibility of the EHDI program, create networking opportunities, strengthen collaborative relationships with stakeholders and raise awareness about the importance of newborn hearing screening and timely follow-up.

Better Hearing and Speech Month (BHSM) is celebrated each May and provides an opportunity to raise awareness about pediatric hearing health issues and the services offered by the EHDI program. Since 2009, NC-EHDI has shared hearing health information with stakeholders and the general population during BHSM. During this month, the program has written and disseminated articles about hearing health topics, developed Public Service Announcements (PSA), conducted mass hearing screenings and provided educational programs across the state. During this grant cycle, we plan to add social media to our repertoire for disseminating information.

Medical home education is a top priority for the EHDI program, the EHDI Advisory Committee and the QI team. Establishing relationships with busy medical providers is challenging. The QI team has recommended that we build on the success of a residency lunch and learn program at one NC medical school and use quality improvement methodology to develop a newborn hearing screening training module for other residency programs.

**QI Change #1 for Objective 4.1:** Develop a newborn hearing screening training module for NC medical center residency programs in Family Practice and Pediatrics.

**BACKGROUND:** In 2009, the Project Coordinator and Chair of the EHDI Advisory Committee, who is also a pediatric audiologist, collaborated on the development of a lunch and learn program for pediatric residents at one of the medical schools in North Carolina. Since then, the training program has been presented annually and revised based on feedback from the attendees. The program explains the EHDI process and the key role of the medical home. The program has received positive reviews and the residents found the information very helpful. Based on the program's success, the pediatric audiologist is planning to develop a training module to share with other residency training programs in the State.

**PLAN:** (1) Develop presentation. (2) Develop information handouts. (3) Identify a contact at one of the residency programs who would be interested in using the presentation in the residency training program. (4) Develop short evaluation tool to be used immediately after presentation.

**DO:** (1) Use the presentation and materials in a medical school residency training program. (2) Conduct an evaluation of the presentation and materials.

**STUDY:** Questions to ask: Based on the evaluation results...

- Did the residents find the information in the presentation useful? Did they already know the information that was presented?
- Did the residents like the presentation format?
- Is there other information the residents would like covered in the presentation?
- Is this a good format for educating residents about the EHDI program, newborn hearing screening and hearing loss?
- Should there be further testing of this method of providing the information? Should another method of providing the information be explored?

**ACT:** Based on the success of the current lunch and learn program, we expect that the resident training module will be well-received. Modifications will be made to the presentation content and format as needed based on the feedback from residents attending the training program. There are five pediatric resident training programs and 14 family medicine resident training programs across the state. The key factor to spreading this across the state is identification of a partner at each of the residency training programs who would be willing to share the presentation with their residents and/or developing webinars that can be accessed online. Developing collaborative relationships with each of the resident training programs will take time. The EHDI Chapter Champions will be involved in making these new connections and helping us spread this change across the state. Based on the success in this setting, we plan to share the presentation during other provider meetings including grand rounds and professional meetings. Additional PDSA testing may be needed given the setting change.

**QI Change #2 for Objective 4.1:** Incorporate video clips of parents sharing their personal stories into training sessions for key stakeholders.

**BACKGROUND:** Personal stories help us connect emotionally to a topic. They help us remember information and the stories are often retold and shared with others. The QI team and the EHDI Parent Consultant feel very strongly about the impact personal stories have on spreading a message. The Parent Consultant is spearheading the effort to include video clips of North Carolina families that have children with hearing loss sharing their journey and experiences into educational presentations for key stakeholders.

**PLAN:** (1) Meet with the Department of Health and Human Services (DHHS) Office of Communications regarding the development of video clips. (2) Identify families interested in sharing their story. (3) Prepare two video clips in collaboration with the DHHS Office of Communications.

**DO:** (1) Insert video clip(s) into an educational presentation. (2) Present video clip as part of one presentation. (3) Conduct an evaluation of the presentation with questions specifically addressing the inclusion of personal stories.

**STUDY:** Questions to ask:

- Determine the interest level of families telling their own story.
- What did the presentation attendees think about the inclusion of personal story videos?
- Which video clip was preferred? Why?
- Should there be further testing of this method of providing the information?

**ACT:** The expected outcome is that inclusion of personal story video clips in educational presentations will be positive. The Parent Consultant is confident that we will be able to find families who are willing to share their stories. This change should not require lengthy PDSA testing cycles due to the numbers of presentations done each year by the EHDI team. This change could be spread with ease since the video clip files can be shared with the EHDI team and they can be inserted into current educational presentations.

#### **Continuing activities for Objective 4.1:**

The QI team determined it was important to continue providing the following targeted education activities during this grant period.

##### Medical Home Education

- Provide “Just in Time” education to primary care providers on newborn hearing screening and follow-up soon after a patient is diagnosed with hearing loss
- Provide medical homes with parent-developed “Time is Crucial” posters aimed at educating providers and parents about the importance of newborn screening follow-up
- Collaborate with American Academy of Pediatrics (AAP) Chapter Champions on effective strategies for PCP education
- Evaluate results of National Center on Hearing Assessment and Management (NCHAM)/Boys Town physician survey completed in 2013 by NC pediatricians. Results from the survey will be used to develop resources for physicians related to hearing screening and follow-up.

##### Head Start programs, Home Visiting programs and other key stakeholders

- Provide training on the hearing screening process, resources for children suspected or identified with hearing loss, and normal speech development
- BHSM material distribution
- Provide parent-developed posters

#### Families with or at-risk for hearing loss

- Provide Family Care Notebooks in collaboration with EIDHH
- Coordinate Counseling, Aural Rehabilitation, and Education (CARE) workshops
- Provide verbal and written educational information to families about infant diagnosis and communication development

#### Pregnant women

- Provide prenatal education and materials about newborn hearing screening and follow-up
- Provide information to MIECHV home visiting programs to provide to at-risk, first time mothers

#### General population

- BHSM materials and activities

### **System Goal 5: The NC EHDI Program will promote collaboration among agencies and individuals working in the interest of identifying and serving children who are deaf or hard of hearing in a culturally and linguistically competent manner.**

Collaboration occurs at all steps in the 1-3-6 EHDI process. The EHDI staff has developed strong collaborative relationships with all birthing facilities, pediatric audiologists and early intervention providers throughout the State. These relationships are essential to the implementation of a successful EHDI program. The collaborative relationships with other key stakeholders including families, medical homes, midwives, Local Health Departments, home visitation providers, the ECU Telemedicine Center and Department of Communication Disorders, NC Pediatric Society, intra-office personnel in DPH such as the Coordinator of Minority and Special Populations services, Community Transformation Grant, Chronic Disease, and other agencies are program strengths. The EDHI Advisory Committee is a body of representatives of the key collaborative stakeholders. Services for individual children with hearing loss, as well as general issues, are discussed during quarterly service coordination meetings with EHDI personnel, BEGINNINGS staff, EIDHH teachers and representatives of large pediatric audiology practices.

The EHDI Program collaborates with midwives for development of systems that ensure infants born at home have access to newborn hearing screening. Hospitals, Local Health Departments and other providers collaborate with NC-EHDI to meet the needs of families who need free hearing screens or rescreens. Working in collaboration with the EIDHH program and parents, the EHDI program developed the Family Care Notebook. This notebook provides structure for parents who have multiple appointments, audiograms, business cards and other information to organize after their child is diagnosed with hearing loss. EHDI and the CARE project have joined forces to offer nine CARE workshops across the state with attendance of 86 parents and 47 professionals. The EHDI program has made it a priority to strengthen collaborative relationships with families of children with hearing loss. The EHDI Parent Consultant and parents across the state have been instrumental in the: (1) development and review of program materials such as Hearing Healthcare Map and posters, (2) facilitation of CARE workshops, and

(3) provision of parent-to-parent support services. The dissemination of information is also a collaborative effort involving the NC DHHS Office of Communications, local newspapers, radio stations, and organizational newsletters.

**Objective 5.1:** Develop new and strengthen existing collaborative relationships with programs and agencies involved with families who have a child with or at risk of having hearing loss.

**Continuing Activities for Objective 5.1:**

- Quarterly meetings of the EHDI Advisory Committee to discuss service gaps, possible solutions and suggested quality improvement strategies
- Collaborate with MIECHV programs and LHD Care Coordinators for Children on reaching and educating families identified as high risk for loss to follow-up
- Attend quarterly service coordination meetings with BEGINNINGS for Parents of Children who are Deaf or Hard of Hearing, and EIDHH and other stakeholders
- Participate on the NC Agenda for Deaf Education committee
- Distribute email updates quarterly with articles and information of interest to collaborators.

**RESOLUTION OF CHALLENGES**

The North Carolina Division of Public Health (DPH) has a long standing commitment to promoting programs for young children and their families. The EHDI Program is housed within the Children and Youth (C&Y) Branch. There are multiple opportunities to learn from C&Y leaders, collaborate with DPH staff in other projects, and obtain support in identifying solutions to the challenges presented in reducing the number of children lost to follow-up throughout the EHDI process. The grant work plan will build on the strengths of ongoing and successful EHDI efforts, anticipate known challenges, and document evolving concerns.

The EHDI Advisory Committee is an active group of stakeholders that examine needs and suggests solutions for implementation and contribute to long-range planning. Meetings in 2014-2017 will continue to focus on lost to follow-up, ways to further support North Carolina families who have a child with hearing loss, educational activities targeting stakeholder groups and how to address the challenges the proposed grant work plan will encounter.

Collaborative relationships with birthing facilities, pediatric diagnostic audiologists, early intervention providers and families facilitate the early identification of problems so that challenges can be addressed as soon as possible. On-site technical assistance provided by the regional consultants will be a strategy used to promote newborn hearing screening and follow-up best practices. Successful changes identified during the NICHQ learning collaborative and the NC CPHQ QI 101 training collaborative using PDSA methodology will continue to be incorporated into hospital trainings and technical assistance activities. The Project Manager and Project Coordinator will document requests for training and ensure the availability of personnel to support planning and implementation of training related to project goals. Consultation documentation and the hospital annual program plans will identify what is successful in the on-site programs and what components need improvement.

Stakeholder and staff buy-in during CQI activities can be a challenge. The C&Y Branch is an environment where QI participation is encouraged and supported. Twenty-one branch staff members have completed NC CPHQ QI 101 training, four additional EHDI staff members completed the NICHQ learning collaborative, three branch staff members completed NC CPHQ QI Advisors training, and two Best Practices Unit data managers are being trained as QI team coaches. Each unit within C&Y is represented on the C&Y QI Workgroup, including professional and administrative staff. This workgroup educates staff about QI methods, serves as a resource for any staff wishing to implement QI tools, serves as a resource to staff writing QI plans for grant applications, serves as a central communication hub for all current Branch QI projects, suggests possible Branch QI projects, and helps create QI project teams. An EHDI Program state QI team has been formed using parents, other stakeholders, data managers, and EHDI staff members to identify and prioritize possible change strategies leading to program improvement. LQI teams will meet more frequently to plan and assess progress on individual PDSAs and to evaluate their effectiveness.

Documenting results of screening, rescreening, audiologic evaluations, amplification fitting and early intervention in the State data tracking and surveillance system is critical for reducing loss to follow-up in the EHDI process. State legislation in North Carolina mandates newborn hearing screening. Reporting of screening after 6 months of age and reporting of diagnostic evaluation and/or amplification fitting after 12 months of age is not required. There are no fiscal or other consequences for institutions and individuals who do not report screening results. To address this challenge, the Program will continue to provide training on the use of Hearing Link to birthing/neonatal facility staff and audiologists. Primary care providers, CDSA offices, Head Start Centers and midwifery practitioners will also be trained to use Hearing Link during this initiative. Training will emphasize the importance of prompt entry of information for all children regardless of age, the need for detailed documentation and the valuable role of staff in reducing lost to follow-up. The Follow-up Coordinator will support better tracking and improved documentation activities.

Coordination of data systems will continue to be a concern. The solution will involve multiple entities; however, the statewide use of Hearing Link will strengthen NC's efforts in tracking babies through the EHDI system. Ongoing training and technical assistance provided to users of the data tracking and surveillance system will facilitate the tracking efforts at each of the 1-3-6 steps.

The Program has developed many new educational materials and resources during the last funding cycle. There are challenges related to updating materials, assuring that materials are used consistently by all of the facilities and fulfilling requests of new materials in a timely manner. The regional consultants will be responsible for assuring that educational materials are available and they will continue to train the facilities on the incorporation of these new materials into the newborn hearing screening program. Educational materials and other resources will be made available on the NC EHDI website for prompt access. Families, birthing/neonatal facility personnel and other stakeholders will be involved in the development of new materials and the decision to incorporate these materials into the Program. Obtaining and providing written materials in languages other than English is an additional challenge. Translation resources available through the Division of Public Health and outside sources will be utilized. All materials will be culturally-sensitive and family-friendly. Funding reductions could limit the

ability to translate materials into additional languages, distribute educational and resource materials, or develop new training material. Options will be explored in conjunction with the NC DHHS Office of Communications.

Infant diagnostic audiological services across the State are more concentrated in populated areas, with 79% located in the Piedmont region. The Mountain and Coastal Plains regions have fewer services and greater distances for families to travel to obtain pediatric audiological services. When families live near the state border, they may go into the nearby states for services which makes follow-up difficult to document. This initiative provides teleaudiology services to families in the eastern part of the State, and through the provision of diagnostic equipment, complete infant audiological diagnostic services were recently made available in the western part of the State. As a result of reduced funding, the teleaudiology project may not be able to meet existing need for service. The Program Manager is working with East Carolina University to identify other possible sources of funding.

Collaboration with medical homes is addressed within multiple projects throughout this project. This ongoing work will be integrated with grant efforts to identify effective strategies to educate health care providers, including midwives, about hearing screening, risk factors for hearing loss, late-onset hearing loss and caring for a child with hearing loss. A challenge will be locating the multiple midwifery providers and identifying contacts for follow-up services within private physician practices. Efforts will be made to continue our collaborative work with the Women's Health Branch, North Carolina Pediatrics Society and Pediatric Practice Managers in obtaining contact information for midwives and other health professionals serving newborns.

The recognition of challenges is critical to designing effective change. The fragmentation of efforts can be minimized and loss to follow-up will be reduced with consistent, ongoing training, collaboration with stakeholders and dedicated follow-up support.

## **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

The NC-EHDI Program conducted a formal Program review in 2005 that resulted in renewed emphasis on improving data collection and reporting. The Program Development and Evaluation Manager functions as the CDC EHDI Cooperative Agreement Coordinator and is playing a vital role in designing and improving the hearing screening data capacity of WCSWeb Hearing Link, NC's web-based EHDI data system. Working in conjunction with computer programmers, this position is assuring a data system that will meet the needs of the program. Improvements planned for Hearing Link will enable us to: (1) capture the specific data fields needed; (2) create the data reports required to verify progress on the national 1-3-6 goals (i.e., hearing screen by 1 month of age, hearing loss diagnosed by 3 months of age, and enrolled in early intervention services before six months of age); (3) monitor outcomes, and (4) document a reduction in loss to follow-up. The Follow-Up Coordinator position will work closely with the Evaluation Manager to develop and generate bi-annual data reports for each birthing facility and pediatric audiology practice, including a calculation of their loss to follow-up numbers. In addition, loss to follow-up data will be generated for specific demographic groups within the state, which can be tracked for intervention and improvement.

For process evaluation, program success will ultimately be demonstrated by local adherence to model program delivery standards. We will collect program level process data which will be critical to determine if local programs are meeting EHDI service delivery goals and adhering to best practice standards. Surveys will be developed, disseminated, and analyzed for a variety of audiences throughout the grant cycle. The purpose of the surveys will include identifying current knowledge, perceptions, and attitudes regarding UNHS, follow-up services, childhood hearing loss, normal speech/language and hearing development, and service delivery models. Additionally, we will collect qualitative information regarding obstacles to implementation and how they are addressed. This information will enable us to learn what aspects of implementation are successful and what aspects are problematic and may require modification. Examples might include: language or cultural obstacles, inadequately adopted program materials, training deficiencies, distance from work site to client and between clients in rural areas, or health insurance obstacles related to age-appropriate services/hearing-related devices.

Hearing Link will also be utilized to monitor the impact of the Western NC Pediatric Audiology Center and telemedicine projects. Specific variables to be evaluated include age at diagnosis and numbers of children receiving diagnostic evaluations following a “refer” result on newborn hearing screening. The rate of change will be evaluated for each of these variables for the three projects.

In addition, the EHDI Program maintains a database of consultations, trainings, and technical assistance provided throughout the State. Modifications will be made to this database to ensure that grant activities are captured. These consultation outcome measures will be used to document the frequency and type of support given to birthing facilities, families, and service providers. We will continue to utilize formal training evaluations for all training provided by EHDI staff, and will develop and implement such evaluations for new target audiences and/or training topics.

CQI methods and tools will be employed throughout this grant project period. Several EHDI staff and stakeholders participated in the NICHQ learning collaborative in 2009. Additionally, the Program Development and Evaluation Manager, Follow-up Coordinator, and one speech language consultant participated in a QI 101 training collaborative provided by the NC CPHQ in 2011. The CPHQ is a national resource for quality improvement among public health organizations that originated from the North Carolina center. The CPHQ collaborates with local, state, and national partners to transform the public health system to foster and support CQI by providing training and tools, sharing what works in public health, promoting performance measurement, leading strategic QI initiatives, and engaging leadership to drive organizational change. The Evaluation Manager and another data manager from the Best Practices Unit work with the CPHQ by providing coaching to new QI 101 teams. The EHDI program will continue the partnership with the CPHQ during this project.

EHDI Program outcome measures and training documentation will be reviewed and analyzed by the Project Coordinator to evaluate the effectiveness of grant activities and suggest needed modifications. The Advisory Committee will receive regular updates on the activities of this grant and their input and suggestions will be incorporated.

## **ORGANIZATIONAL INFORMATION**

The NC-EHDI is organizationally located in the NC Department of Health and Human Services, Division of Public Health (DPH). It is housed in the Women's and Children's Health Section, C&Y Branch, in the Genetics and Newborn Screening Unit which also includes the Metabolic Screening Follow-up Program. The WCHS Chief serves as the NC State Title V Director and holds primary responsibility for developing systems of care that protect and promote the health and well-being of women, infants, and children, including children with chronic special health care needs. The C&Y Branch Head is the Title V State Director for Children with Special Health Care Needs.

The primary purpose of the C&Y Branch (see Attachment #5 for organizational chart) is to develop and promote programs and services that protect and enhance the health and well-being of children and families. The Branch is composed of a broad array of programs and initiatives that target public health and related programs for children from birth to 21 years. The C&Y Branch strives to enhance the health, growth, and development of all children through health promotion, prevention, early identification, treatment, and intervention. Whenever possible, services are offered within family-centered, culturally and linguistically competent, community-based systems of care. The Branch sponsors a Family Advisory Council to advise and assist with program planning, implementation, evaluation, and outreach.

NC-EHDI is part of the state Title V maternal and child health services and functions in close collaboration with a number of other programs for children with special health care needs. The Program is administered by staff in the Genetics and Newborn Screening Unit, which includes a Unit Manager, the EHDI Program Manager, the EHDI Project Coordinator, 12 regional speech-language pathology and audiology consultants, and the Parent Consultant. Data management for NC-EHDI is administered through the Best Practices Unit, which includes a Unit Manager, the EHDI Development and Evaluation Manager, the EHDI Follow-up Coordinator, an administrative assistant and two centrally located data processing assistants.

The central tracking staff consists of the Follow-up Coordinator hired with HRSA funding, one administrative assistant hired with CDC funds, and two data processing assistants hired through a combination of state and FFP funds. Led by the Follow-up Coordinator, central tracking staff is responsible for obtaining hearing screen/rescreen results for records that are incomplete in Hearing Link. The central staff tracking process typically consists of calling hospitals, primary care providers, local health departments, audiologists, and parents.

The regional consultants include six SLCs, two of whom are employed through DPH. The other four SLCs are contract employees through local agencies. All of these employees are supported through state and FFP funding. The SLCs provide: 1) technical assistance, training, and consultation to birthing facilities on best practices for running a newborn hearing screening program, 2) review quarterly hospital specific data and consult with hospitals whose performance needs improvement, 3) Hearing Link training, consultation to families, hospital staff, and other providers on communication development, 4) support and assistance to families in identifying and accessing appropriate screening and diagnostic services, 5) when necessary, initial hearing screenings and re-screens for families that do not have access to other services, and 6) educational programs and consultation for individuals, community groups and agencies regarding newborn hearing screening, language development and communication related issues.

There are four CHACs employed through DPH, one 0.56 FTE CHAC funded by HRSA funds, and another .65 FTE CHAC who is a contract employee through a local health department. The audiology consultants provide: 1) consultation to families and providers following diagnosis of hearing loss, 2) visits with primary care providers for each of the children identified with hearing loss to provide a manual with information about the EHDI process and the specific child in their care, 3) tracking of children who have been identified with hearing loss from diagnosis through early intervention services, 4) monitoring of children with a hearing loss from birth to age 21, 5) training and consultation to pediatric audiologists, physicians, and other child service provider agencies on recommended practices in diagnosis of hearing loss and amplification fitting, and 6) educational programs for community groups, local health departments, physicians groups, Head Start programs, early intervention programs, home visiting programs and other agencies regarding hearing related issues.

Cognizant of the fact that the NC population is culturally and linguistically diverse, the C&Y Branch supports a Coordinator for Minority and Special Population Needs to provide leadership across the Branch in conducting effective outreach and service delivery to various ethnic, cultural and socio-economically diverse groups. The Coordinator provides professional support on diversity for families, colleagues and professionals within and external to the Branch. However, the responsibility for delivery of culturally competent services is not the sole responsibility of this one individual. Delivery of culturally competent services is a performance goal of the Branch. Staff members are afforded opportunities to keep abreast of health disparity issues and culturally competent approaches through a monthly lunch and learn session that can be accessed in person or through phone conferencing. Specific training needs may be addressed through on-site presentations or webinars provided by the Coordinator for Minority and Special Population Needs or invited experts. The Genetics and Newborn Screening Unit Manager and five other members of the EHDI team are African American. Regional consultants have all resided in the areas they serve for long periods of time. They know the specific needs of the populations of their communities, are familiar with local resources and service providers, and are uniquely qualified to assess needs and offer suggestions for improvement within their regions. These staff members constitute more than 100 years of combined experience working with diverse clients and providing culturally and linguistically leadership and training.

In 2012, members of the EHDI Team participated in a Learning Collaborative through the CPHQ. The principal aim of this QI effort was to streamline the process of tracking children from hospital screening through completion of the screening process. EHDI Team members were able to identify problems, redundancies, and ineffective procedures and develop strategies leading to greater efficiency and effectiveness in the system. The QI work done by the EHDI team was hailed as exemplary by CPHQ and has been widely shared among other units in DPH embarking on their own QI processes.