

## **Introduction**

North Carolina's Early Hearing Detection and Intervention (EHDI) Program has had many successes. All 88 birthing/neonatal facilities in the state offer initial newborn hearing screening services prior to infant discharge. There is clear and ongoing support from the Title V agency in which the program is organizationally housed, the birthing/neonatal facilities that perform initial newborn hearing screening, and the Early Hearing Detection and Intervention Advisory Committee. Initial newborn hearing screening rates across North Carolina are excellent; 98.2% of infants born in North Carolina in 2007 were screened for the presence of permanent hearing loss and 96.3% of those infants received their initial newborn hearing screening prior to 1 month of age. Of the 131,101 infants screened at birth, 129,809 (99%) were considered as "passed" after the rescreens were performed on the group of infants who did not pass initially. These figures show an overall "refer" rate of one percent of infants screened for permanent hearing loss at birth. Rescreens occur at birthing facilities and other community settings such as physicians' offices and local health departments. For families of some infants, hearing screening is obtained through the services of Division of Public Health EHDI Program staff.

Both the EHDI Program and the Newborn Metabolic Screening Program follow-up are provided by the Genetics and Newborn Screening Unit, as noted in the Organization section of this application. North Carolina's Division of Public Health EHDI Program staff track infants through the screen-rescreen-diagnosis-intervention process. These staff members have forged strong interagency partnerships with a variety of public and private agencies, such as birthing/neonatal facilities, local health departments, early intervention agencies, and North Carolina's Medical Home Initiative.

In 2007, of the 1,292 infants who did not pass the screening, only 566 (43.8%) were reported to have been referred for audiological diagnosis. For the remaining 726 infants, it is unclear if they were not referred properly following rescreen or if the referral was made and not reported correctly. There has also been some difficulty determining the exact number of those infants who were referred for audiological diagnosis who received that evaluation and/or are confirmed as having hearing loss. In 2007, of the 566 infants who were reported to have been referred for audiological diagnosis, completed diagnostic audiological evaluations were reported for 481(85%). Confirmed hearing loss was reported for only 188 (39.1%). Anecdotally, the Program's staff is aware that many more very young children are seen for diagnosis, amplification, and intervention than are reported. There appears to be an under-reporting of further diagnostic evaluations for infants suspected of having a congenital hearing loss as well as an under-reporting for those infants with confirmed hearing loss who receive amplification and early intervention services.

In September 2006, North Carolina began the transition to full implementation of Women's and Children's Section Web Hearing Link (WCSWeb Hearing Link), a web-

based direct data entry reporting and tracking system for newborn hearing screening and follow-up results. Currently, 43 of the 88 birthing/neonatal facilities and 136 audiologists across North Carolina are using WCSWeb Hearing Link. Those 43 birthing/neonatal facilities accounted for 58.3% of all live births across the State in 2008. There are plans to have all 88 birthing/neonatal facilities, as well as all pediatric audiologists performing diagnostic audiologic evaluations and/or amplification fitting services for young children, using WCSWeb Hearing Link by the end of 2009. Plans also include having early intervention service providers using it by the end of 2010.

North Carolina is now in its second year of the HRSA funded EHDI grant. The second year activities for the existing grant focus on reducing loss to follow-up between failed rescreens and audiological diagnosis. By increasing access to sites capable of providing auditory evaluations for infants, this supplemental grant application will decrease the loss to follow-up between rescreen and diagnosis, as well as the age at which diagnosis is occurring in two regions of North Carolina.

North Carolina is fortunate to have established telemedicine programs. The eastern counties in North Carolina are historically medically under-served. In an effort to improve the health of the region's residents, one of the first telemedicine programs in the country was established. The telemedicine program in eastern North Carolina has been in continuous operation since its inception in 1992, making it one of the longest running clinical telemedicine operations in the world. The program has received national recognition and been recognized as one of the "Top 10" telemedicine programs by *Telehealth Magazine*. They provide clinical telemedicine services, conduct telemedicine research, and educate health care providers and the public about telemedicine. We will expand their services to include infant audiology evaluations in the "Teleaudiology Project."

The "Teleaudiology Project" will reduce the number of infants from 35 counties in the eastern part of North Carolina (see Map – Attachment 1) who are lost or have delayed follow-up after referring on a hearing rescreen. The lack of services available in the eastern part of the state creates a unique need and opportunity for audiological services that can be provided through non-traditional means. It is anticipated that with the availability of services that would greatly reduce the distance and time involved in securing the audiological evaluation, there would be 44 more children each year that would be diagnosed by the recommended 3 months of age. The grant will fund the start-up of a project involving a university that has an active telemedicine program and is part of the UNC System, and NC Division of Public Health (DPH). Infants will travel to the remote telemedicine site closest to their home. There a Child Health Audiology Consultant (CHAC) from DPH will operate the audiology and telemedicine equipment and monitor the child. The effectiveness of the audiology equipment, given the potential for interference from other electrical sources, will be evaluated and suitable means of overcoming any problems will be determined. An audiologist at the university telemedicine hub site will be evaluating the results of testing. If the child has a hearing loss, the audiologist with the child will ensure that the family is referred to intervention services immediately.

As the feasibility of the telemedicine system is determined, different options for providing this service will be explored. Initially, fourth year audiology students will be involved at the telemedicine hub site at the university. Consideration will be given to the efficacy of having them travel to the remote sites to work directly with the child while the supervising clinical audiologist remains at the hub site for the evaluation. Other options for local sustainability will also be explored. One avenue for local services may be training child health nurses from local health departments to run the audiology and telemedicine equipment and work directly with the infants and families at the time of diagnosis. Agreement Addenda between DPH and local health departments are in place. These support direct clinical services for children in each community; a portion of the funding is flexible and could potentially be used for these services. Another option might be training hospital personnel who are already involved with the local newborn hearing screening programs, since six of the telemedicine sites are within hospitals that provide newborn hearing screening and the nurses are familiar with automated auditory brainstem response (AABR) screening equipment.

Additionally, to decrease loss to follow-up and delayed diagnosis in the south central part of the state (See Map – Attachment 1) we will provide diagnostic equipment to an ENT practice. The practice includes two audiologists experienced and interested in doing pediatric evaluations, but does not at this time have the equipment needed to provide these services. By providing diagnostic services locally, we anticipate that 36 children each year will be able to receive the audiological evaluation by 3 months of age.

The grant will also fund the development of materials to help support parents throughout the entire state. A “road map” will be developed that will be given to all parents when their child fails the initial hearing screening. It will provide the steps needed to “navigate the NC EHDI system.” For all parents whose child is diagnosed with hearing loss, a “Family Support Kit” will be developed to assist in organizing the needed information about their child’s hearing loss. These grant activities will be tested initially with a small number of families and will be analyzed for effectiveness and modified as needed before they are widely distributed throughout the state.

This supplemental grant project will encompass program objectives which relate to the Healthy People 2010 initiative. Specifically, grant activities will relate to the following goals: (1) increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months; (2) increase the proportion of persons who have had a hearing examination on schedule; (3) increase the number of persons who are referred by their primary care physician for hearing evaluation and treatment; and (4) increase access by persons who have hearing impairments to hearing rehabilitation services and adaptive devices, including hearing aids, cochlear implants, or tactile or other assistive or augmentative devices.

## Needs Assessment

North Carolina has one of the largest birth rates in the nation. The data referenced in this needs assessment were obtained from WCSWeb Hearing Link, unless otherwise indicated. Annual births have increased from 116,887 live births in calendar year 2004 to 133,450 live births in 2007. The demographic breakdown of babies born in 2007 is as follows: 58.2% White, 23.1% Black, 14.2% Unknown, 2.2% Asian, 1.0% American Indian, 1.0% Multi Race, 0.3% Hawaiian/Pacific Islander. Additionally, 22,335 (16.7%) infants born in 2007 were of Hispanic origin.

North Carolina currently has 88 birthing/neonatal facilities. These centers account for 99.4% of the live births. Only 777 (0.6%) live births reported in 2007 were born out-of-hospital. All of the birthing/neonatal facilities (100%) offer newborn hearing screening services prior to the infant's discharge from the facility. The average referral rate for screenings completed at these facilities for babies born in 2007 was 3.95%.

Reports of hearing screening and follow-up results come to the EHDI Program in three different forms: (1) paper forms submitted by mail or fax, (2) electronic file transfer from the North Carolina State Laboratory of Public Health, and (3) direct data entry into WCSWeb Hearing Link. Following a two-year pilot project with six birthing facilities, North Carolina began the transition to full implementation of WCSWeb Hearing Link, a web-based direct data entry reporting system for newborn hearing screening and follow-up results, in September of 2006. Currently, 43 of the 88 birthing/neonatal facilities are using WCSWeb Hearing Link. As a result of this transition, North Carolina has identified numerous data system design changes which are needed to improve data. In December 2006, an audiologist was re-assigned to the role of Program Development and Evaluation Manager to oversee the continued development and implementation of WCSWeb Hearing Link and quality assurance activities related to data collection and EHDI Program activities. The state received a three-year CDC Cooperative Agreement in July 2008 for the purpose of improving the data system and improving tracking and surveillance activities.

WCSWeb Hearing Link allows access to data immediately and has vastly improved North Carolina's ability to report complete data to the Centers for Disease Control and Prevention and other agencies. However, it is currently unable to accurately capture the number of infants lost to follow-up between the screening and rescreening. Original data system design did not distinguish initial/inpatient screening from rescreen/outpatient screening. As part of the CDC Cooperative Agreement, we are actively working to make changes to WCSWeb Hearing Link to address this issue. The number of infants lost to follow-up, or for whom no documentation of hearing screening exists was 1,597(1.2% of live births) in 2007. Most of these infants had no screening results or incomplete screening results reported. This indicates a need for continued development of the data system as well as additional technical assistance and training regarding effective screening techniques and reporting requirements.

Of the 1,292 infants born in 2007 who were reported to not pass the rescreening, only 566 (43.8%) were reported as referred for diagnostic audiologic evaluation. Diagnostic audiologic evaluation was reported to be completed for 37.2% (481) of the infants not passing the screen/rescreen process. However, only 186 of the reported completed diagnostic audiologic evaluations (38.7%) were completed by 3 months of age. The number of infants lost to follow-up, or for whom no documentation of diagnostic audiologic evaluation exists, between rescreening/outpatient screen and audiologic diagnostic evaluation in 2007 was 395 (30.6% of those not passing the rescreen). The remaining 416 children were reported as either deceased or declined services. These data support a need for further education of physicians regarding the importance of making a referral for diagnostic evaluation following a failed newborn hearing screening as well as the need for additional technical assistance and training with audiologists regarding reporting requirements.

For infants born in 2007, 140 were reported to have confirmed hearing loss with amplification recommended. Of those 140 children, 76 (54.3%) were reported as receiving amplification. Only 27 (35.5%) of those fit with amplification were reported as receiving amplification by the age of 6 months. Additionally, 64 (45.7%) were lost to follow-up or had no amplification selection results reported. This indicates the need for additional technical assistance and training with audiologists regarding reporting requirements and training with physicians on the importance of habilitation services for young children with diagnosed hearing loss.

Currently, data regarding young children with diagnosed hearing loss enrolled in early intervention services is extremely limited in North Carolina. The North Carolina Early Intervention Infant-Toddler Program does not maintain child-specific data based on diagnoses and is, therefore, unable to provide statistics on the number of children with diagnosed hearing loss who are enrolled in Part C services. Some young children with diagnosed hearing loss receive services from the North Carolina Office of Education Services' Early Intervention for Children who are Deaf or Hard of Hearing Program (EIDHH). EIDHH reported that 172 children born in 2006 were enrolled in their program, with 77 (44.8%) of those children enrolled in services by the age of 6 months. This limited data supports our attempts to continually improve our efforts for increased collaboration between the EHDI, Infant-Toddler, and EIDHH Programs in North Carolina regarding data collection and reporting needs. Improved data collection and reporting of intervention data is addressed as part of the activities in the CDC Cooperative Agreement.

North Carolina requires that newborn hearing screening results and metabolic screening results be reported to the State Laboratory of Public Health. As a result of this connection with metabolic screening, each child has a designated primary care physician. The State Laboratory of Public Health defines primary care physician as the "physician of record at the time the newborn screen is ordered". For the purpose of this grant application, the same definition will be used for determining the number of infants and families with a medical home. In some cases, records have been updated to accurately reflect the primary care physician of the child after discharge from the birthing facility.

There are 130,359 (97.7%) children born in 2006 who have a reported medical home. There is a need to collect accurate information about the primary care physician, medical home, following discharge from the birthing/neonatal facility for children with suspected and/or confirmed hearing loss. This will continue to be addressed by better educating birthing/neonatal facilities about the importance of verifying the identity of the child's primary care physician before the parents leave the hospital and at the time of the rescreen. This will also be addressed by further development of the WCSWeb Hearing Link and better educating birthing/neonatal facilities, audiologists, and early interventionists on reporting requirements.

Another issue affecting loss to follow-up is the documentation of hearing screening results and the explanations of newborn hearing screening given to families. The materials used and the quality of interactions with families vary greatly from facility to facility. North Carolina has families who speak many languages, though most written material is provided in only English or Spanish. There is a need to obtain written information in additional languages. There is also a need for more ready access to interpreters when working with families who speak languages other than English.

There are currently family-to-family support groups in five areas of the state. Parent educators with Beginnings for Parents of Children Who are Deaf or Hard of Hearing, teachers with the EIDHH program and EHDI Program staff encourage family-to-family support and offer to assist in connecting families to one another during home visits and other contacts with families of children with hearing loss. As part of this supplement, input is needed from families about their perceived support needs around the diagnostic audiological evaluation part of the process, so that further activities can be developed which will adequately meet the needs of families.

North Carolina currently has 18 audiology practices, with varying numbers of audiologists per practice, that can complete infant diagnostic audiology evaluations. Criteria for inclusion on the list of infant audiology practices were approved by the EHDI Advisory Committee. In order to be included on the list, practices must be fully equipped to conduct frequency specific auditory brainstem response (ABR), bone conduction ABR, visual reinforcement audiometry (age appropriate), otoacoustic emissions (OAE), and high frequency immittance audiometry and agree to follow established protocols and reporting requirements disseminated by the EHDI Program. All practices submitted their information by self-report.

There are no pediatric audiology practices in the south central region of the state. In the eastern region, only two practices within an area covering 18,141 square miles (39% of the state) see children under the age of 18 months. One of these practices does not accept Medicaid, and the other has a waiting time of several weeks to get an appointment for an infant diagnostic evaluation. Previously there were two audiologists at a hospital in a south central county. They provided infant diagnostics for babies from both of these regions, however one of these audiologists left in January of 2008 and the other left last fall. The hospital plans to replace only one audiologist and that position is not yet filled. Whether or not the hospital will resume doing infant evaluations remains to be seen.

The two regions in North Carolina participating in this project had 197 babies born in 2008 who needed to have audiological evaluations. Of those infants, 113 (57.4%) still have not received audiological evaluations and only 38 (19.3%) were diagnosed by 3 months of age. (See Table 2 – Attachment 1) These regions are largely rural, have high teen pregnancy rates, and significant poverty. In population based studies done in Massachusetts, it has been found that infants are at higher risk of becoming lost to follow-up, if their mothers are: (1) teenagers compared to mothers 20 years or older, (2) non-white compared with Caucasian, (3) publicly insured compared to those whose mothers are privately insured, or (4) living in rural versus urban areas.

The catchment area to be served by the “Teleaudiology Project” is primarily rural farm land in the eastern part of the state. The 35 easternmost counties of the state have several barriers that make completion of audiological evaluations difficult. Travel is complicated by many inland bodies of water over much of the region. In 2007, the population living in the eastern counties of North Carolina had a median income \$6,568 less than that of the state as a whole. The percentage of people living below the poverty level was 18.5% for the region while the percentage for the state was 14.3%. The percentage of Medicaid births in 2006 was 64.2%, which was almost 12% greater than the state percentage of 51.8%.

Also struggling economically is a nine-county rural area covering 4,825 square miles in the south central part of the state. These counties have a Medicaid birth rate of 62.7% and 18.5% of the population lives below the poverty level. The median income is \$6,386 less than the state’s median income.

In addition to poverty, these areas both have unusually high teen pregnancy rates (per 1000), in comparison to both the state and the nation – 76 in the eastern region and 83.3 in the south central region as compared to 63 for North Carolina and 41.9 for the nation. The percentage of mothers who have not completed high school is higher in both of these areas than in the state as a whole, as is the percentage of minority births. (See Indicators Table 1, Attachment 1)

Given the limited income and multiple barriers in these two areas, there is a greater chance of getting the families to bring their infants for diagnosis if it can be completed close to home. In the south central region, we will provide the audiological equipment needed to do infant evaluations for two audiologists practicing within an ENT practice. In the eastern part of the state, we will do a pilot project to explore telemedicine as an option for providing infant audiological evaluations in 11 remote telemedicine sites initially, and will expand to include a site within the south central region during the second budget period of the supplemental grant.

Perhaps more important than the statistics are the stories of two families who have been trying to have diagnostic evaluations completed for their children, despite the many barriers. The first child was born at a local hospital in the eastern region and returned within one month for the rescreen. Following the rescreening at the hospital, the baby was referred to the closest pediatric audiologist, 78 miles away with an estimated driving

time of 1 hour, 45 minutes. The baby showed for the appointment, but was one hour late. The delay was possibly related to the distance from home, difficulty finding the audiological suite once at the hospital, or difficulty understanding directions to the hospital since English is the second language for the parents. Because the baby was late, adequate time was not available for a sedated evaluation. The baby could not be conditioned to consistently respond to auditory stimuli for testing while at this first appointment. Another appointment was scheduled for the baby to return, with sedation time scheduled into the appointment. The family then traveled home, having spent most of one day traveling for the appointment and trying to get their baby to sleep. With no results, they will need to spend another day to complete the diagnostic evaluation for their infant.

Another baby was born at a local hospital and returned within one month for the rescreen. Following the rescreening at the hospital, the physician was notified and he referred the family to the closest audiologist, who is in Virginia. This audiologist is 75 miles away with an estimated driving time of 1 hour and 30 minutes. The family took the baby for the appointment, but the audiology practice was unclear about whether or not the order included sedation, which was needed to complete the diagnosis. The family then had to make a second trip to Virginia, and with sedation a diagnostic evaluation was completed and the child was found to have a profound bilateral hearing loss. Though NC Medicaid is available, because the family received services across the NC border there are many difficulties associated with a non-NC provider. The other option for the family would have been to go to the closest NC site providing infant diagnostics, 130 miles away with an estimated driving time of 2 hours and 30 minutes. All follow-up will need to be transferred to an audiology practice in NC. With the assistance of NC EHDI personnel and the physician's office, the child will receive hearing aids and referrals for early intervention will be made to NC agencies.

Both of these infants could have been diagnosed at an earlier age and possibly without the use of sedation if time and distance were not such prominent barriers to the auditory evaluation process for infants living in eastern NC.

## Methodology

The grant activities will take place over a period of approximately eighteen months, beginning September, 2009. Data for infants born in 2008 indicates that 62 infants (53.4% of those who were referred for diagnosis) from the eastern region and 51 infants (62.8% of the infants referred for diagnosis) from the south central region were not yet diagnosed as of June, 2009. (Table 2 – Attachment 1) Additionally, 25 infants from the eastern region and 21 infants from the south central region were over 3 months of age when they were diagnosed. By the end of the grant cycle, the following objectives will be met: (1) to decrease by 50% the number of infants in these regions who are referred and do not complete diagnostic audiological evaluations by 3 months of age, (2) to decrease by 50% the number of infants in these regions who do not receive amplification prior to 6 months of age, and (3) to increase the percentage of infants with congenital



hearing loss in these regions who are referred for early intervention services before 6 months of age to 75%.

In the south central counties, access to diagnostic evaluations will be achieved by providing equipment to the ENT practice located within the region. The audiologists have experience doing infant evaluations, and will provide the diagnostic services, hearing aid fitting and appropriate referrals for early intervention.

By using an established telemedicine program, we envision that telemedicine technologies, systems, principles and practices will enable the provision of infant diagnostic evaluations where they are needed, when they are needed. Telemedicine is a critical part of efforts to prepare the next generation of health professionals with contemporary skills and knowledge, and this project will likewise prepare the next generation of audiologists.

Currently, the telemedicine conducted in eastern North Carolina consists of initial patient assessments, primary diagnoses, specialty consultation, management and follow-up for patients that were initially seen in-person or via telemedicine. A common urgent request is for a pediatric cardiologist to read an echocardiogram from a remote site via the telemedicine network. Telemedicine programs have been found to improve access to specialty medical care, increase patient convenience, and improve patient compliance and continuity of care. Similarly, a program in Canada that provides audiological diagnostics for infants in remote sites via telemedicine has found that the program reduced travel and costs for families, and increased the ability to initiate supportive services for the identified infants.

The telemedicine program in the eastern region develops and maintains standard operating procedures for telehealth, which are used by the telemedicine coordinators at the telemedicine center, the coordinators at the remote sites, and physicians. The rural coordinators act as the primary facilitator for telemedicine and distance learning activities at their site, and will be responsible for patient scheduling; operating the telemedicine equipment during teleaudiology encounters; training other local clinical staff; obtaining patient consent; and reporting issues and new ideas to the DPH and the telemedicine program. Engineers are on site at the telemedicine center during normal business hours for technical support, troubleshooting, and setting up telemedicine calls and bridging for telehealth.

The telemedicine program consultation center has four tele-consultation booths that are used to receive telemedicine examinations. Each booth is connected to the video-conferencing bridge and can be switched to any site in the network. All lines are encrypted to ensure client privacy. The booths are outfitted with a video camera, two video monitors, microphone, speakers, and an electronic stethoscope receiver. Fourth year graduate students in an audiology program, under the supervision of a professor, will use the equipment to view the ABR tracings and other diagnostic procedures done in the remote site, and will instruct the audiologist at the remote site when different procedures are needed. Each booth also has a computer workstation that the student audiologist will

be able to use to access the electronic medical record and enter diagnostic data in WCSWeb Hearing Link. The student audiologist will be responsible for writing a report on the examination and providing it to the CHAC, the primary care provider and the appropriate referral agencies.

The remote/rural sites usually have both a clinical telemedicine (examination) room and tele-classroom that can use the videoconferencing network. Typically, the telemedicine examination room is equipped with a general view camera, a video otoscope, and an electronic stethoscope. These remote sites will be utilized for infant diagnostic exams. The DPH CHAC will have portable infant diagnostic equipment and will attach the electrodes and transducers needed for ABR. She will monitor impedance and operate the equipment throughout the procedure. She will complete bone conduction ABR and high frequency tympanometry as needed, and will switch from click to frequency specific ABR when needed. The portability of the diagnostic equipment will allow her to travel to all the remote sites to complete diagnostic evaluations for infants throughout the catchment area. The CHAC will be responsible for discussing and explaining the diagnosis with the family and referring for early intervention services when needed.

The advantage of having an audiologist at the remote site for the start up of the Teleaudiology Pilot Project is that she will be able to ensure that all diagnostic procedures are completed using approved protocols and can work through technical difficulties encountered using the diagnostic equipment with the telemedicine equipment. She will be able to develop protocols that ensure optimal care at the various sites. She has experience in explaining procedures and answering questions for parents, and she can ensure that referrals and necessary consent forms are completed. She will be modeling all of these skills for the student audiologist at the telemedicine hub site.

Through participation in this project, the graduate audiology students working under supervision of a clinical professor will acquire better infant diagnostic skills. They will also learn counseling skills for interacting with parents and will become familiar with protocols for referrals for intervention. One definite *advantage* of this project is that it will provide student audiologists with opportunities to learn best practice procedures and acquire skills for completing infant evaluations, help them recognize the need to provide follow-up and intervention referrals, give them experience writing reports on infant evaluations, and train them in the technology and use of telemedicine.

In addition to these major efforts in two regions of the state, materials will be developed to help parents throughout the state “navigate the EHDI system.” A “road map” will be developed that will be provided to all parents when their infant fails the initial newborn hearing screen. This will give parents information about what their next steps are, based on what the outcome has been for their infant in each part of the system. For the parents of children with hearing loss, a “Family Support Kit” will be developed. This will consist of tools to simplify the process of organizing the needed information about their child’s hearing loss, including calendars to keep track of appointments, plastic sheet protectors for hearing tests and individualized family service plans, note pages, lists of questions they may have for various providers and other materials that may prove helpful.

## **First Budget Period (September, 2009 – March 31, 2010)**

The first budget period of the grant is short. Therefore, the majority of activities will be focused on start-up. All of the objectives will be addressed.

### Start-up Activities

A contract will be developed between a telemedicine program and DPH. A university within the UNC System has been identified and is willing to be part of the Teleaudiology Project. Necessary equipment will be purchased. Protocols for all procedures (referring infants for the Teleaudiology Project, scheduling the patients, supervising the student audiologists, billing for audiology and consultation services) will be developed.

### Materials and Resources

Flyers will be developed announcing the new diagnostic site and the new Teleaudiology Project. The Project Coordinator and Administrative Assistant will supply additional educational materials about hearing loss to birthing facilities and agencies that provide rescreens for infants. New “tools” such as postcards that can be sent to families to remind them of rescreen appointments and brightly colored stickers that will go on discharge summaries indicating the status of the infant’s inpatient hearing screen will be provided for these facilities.

Educational materials will be identified or developed specifically for health care providers in both regions. The materials will focus on the need for prompt diagnostic evaluations, the new services available in the targeted regions and how to refer for these services. The role of health care providers in the diagnostic audiological evaluation process and the benefits of early diagnosis will be emphasized. Effective methods of dissemination of information to primary care providers in these regions will be investigated.

Flyers will be developed to inform the public about the Teleaudiology Project. Public awareness materials and specific strategies will be developed to promote the increased access to diagnostic services in both regions, including the importance of timely audiological diagnosis and the need for amplification and early intervention for children with hearing loss

### Training and Technical Assistance

All hospitals and other facilities in these regions will receive additional technical assistance on the need for prompt follow-up after a failed hearing screen. In order for infants to receive their diagnostic evaluations by three months of age, they must have completed the screening process by the time they are one month old. They will receive and share successful strategies at the regional meetings developed in the grant to which this is a supplement.

Physicians will receive training through means such as grand rounds, medical society e-newsletters and written materials on ways to refer children for diagnosis to the ENT practice in the south central region or to the Teleaudiology Project.

### Tracking and Surveillance

The pediatric audiologists in the south central region will be trained to enter data into WCSWeb Hearing Link, as will any audiology students involved with the Teleaudiology Project. Audiologists and health care providers will be asked to use the fax-back method or other exchange of information processes to communicate the results of diagnostic evaluations and other issues.

### Family Support

The EHDI Program will identify community resources and systems for the identification and referral of infants who may not have completed newborn hearing screening. A “Road Map” will be developed to help families navigate the EHDI process if a child does not pass the initial hearing screening. EHDI personnel will continue to provide support to individual families whose children have not passed their hearing rescreening, ensuring that they obtain the needed diagnostic evaluations to determine if the children have hearing loss. The focus will be on identifying and developing resources to ensure the provision of services to families in culturally appropriate settings and multiple languages.

Families whose children have hearing loss will be referred to the closest group that provides family-to-family support. They will be provided with written materials, and referred to Early Intervention for Children Who are Deaf or Hard of Hearing, Part C Early Intervention and the BEGINNINGS Program for Parents of Children Who Are Deaf or Hard of Hearing. A “Family Support Kit” will be developed that includes calendars for appointments, sheet protectors for important papers, a business card holder and other items that will help families keep the information about their child’s hearing loss together and organized.

### Cultural Competency Awareness

The EHDI staff and other professionals participating on the project will be provided with a list of national and state resources on Cultural Competency and encouraged to discuss the materials at staff meetings. Within the Division of Public Health there is a resource library, monthly minority outreach newsletters, programs that present information about specific cultural groups and free on-line webinars about the diverse populations within North Carolina. These webinars focus on providing effective care to families with diverse cultural beliefs, values and behaviors.

### **Second Budget Period (April 1, 2010 – March 31, 2011)**

During the second budget period all objectives will be addressed. For the Teleaudiology Project, sustainability and expansion will be the focus. Expansion to other sites including local physicians’ offices and local health departments will be explored. Sustainability of the project will be the focus at the end of the second budget period with an analysis of the number of evaluations completed and determination if billing of audiology services would adequately cover the expenses of the project.

### Materials and Resources

Educational materials about diagnostic evaluations that were identified or developed specifically for health care providers during the first budget period will be revised as needed. Effective methods of dissemination of information to physicians will be utilized to further their utilization of the pediatric audiology services being provided.

### Training and Technical Assistance

Training and technical assistance will continue for all hospital rescreen personnel, local health departments, primary care providers and others who may be involved in rescreening and need to understand the referral process.

### Tracking and Surveillance

WCSWeb Hearing Link will be utilized to track the success of this project. The audiologists and health care providers will be asked to determine the most effective exchange of information processes, and those means will be used to communicate the results of diagnostic evaluations and other issues.

### Family Support

The EHDI Program will expand supportive services to individual families whose children have not passed their hearing screenings, ensuring that they obtain the needed diagnostic evaluations to determine if the children have hearing loss. The focus will be on identifying and developing resources to ensure the provision of services to families in culturally appropriate settings and multiple languages. The Teleaudiology Project will include a Spanish interpreter to work with the audiology student to provide translation when needed during an assessment. Persons needing translation into other languages will be assisted via Telelanguage, a 24-hour phone service which offers translations into over 150 languages.

### Expansion and Sustainability

This project will explore the efficacy of providing infant audiological evaluations via telemedicine in North Carolina. Concomitantly, in the later part of the grant period the focus will be on long-term sustainability. Avenues for training personnel to be with the infant and working both the telemedicine and the audiology equipment will be investigated. Using graduate audiology students, local health department or hospital personnel may be possibilities. The feasibility of providing teleaudiology in physicians' offices will also be explored.

EHDI personnel will work with local medical providers and leaders of the Lumbee tribe to explore the possibility of providing Teleaudiology in Robeson County. This county has one of the highest percentages of people living below poverty (28.6%) and the largest percentage of Medicaid births (80.5%) in the south central region. Approximately 63% of the births in Robeson County are to minorities, 38.5% of these are to Native Americans. Telemedicine and audiology equipment will be purchased to be housed in an academic facility within the UNC System or a medical facility in the community. The CHAC will provide training for a professional provider to operate the equipment and provide support

to families. Families living in nearby Columbus, Bladen, Hoke and Scotland counties will be referred to this site as well.

Options for providing similar teleaudiology services in rural, underserved areas of North Carolina will be considered in the beginning of the second budget period. The possibility of utilizing telemedicine practices and equipment in sites other than the already equipped telemedicine remote sites will be considered. For example, if equipment issues can be resolved and personnel trained to work with the child, is it possible to do infant audiological evaluations in health departments, physicians' offices or hospitals? Plans include purchasing audiological diagnostic equipment and two sets of mobile telemedicine equipment to be used in possible clinical sites.

**Work Plan**

The EHDI Program Manager (PM), EHDI Project Coordinator (PC), Administrative Assistant (AA) and Program Development Evaluation Manager (PDEM) will work in conjunction with the program regional staff to carryout the objectives and activities outlined below and arranged by Budget Period.

**Activities to Begin in Budget Period One (September 1, 2009 – March 31, 2010)**

Activities	Start Date	End Date	Responsible Staff
<p><b>1. Meetings with Stakeholders</b> Early Hearing Detection and Intervention (EHDI) Advisory Committee will continue to meet quarterly to evaluate the project, discuss service gaps, possible solutions, and suggested implementation strategies</p>	9/09	3/11	PM & PDEM & PC
<p><b>2. Develop and implement contract for telemedicine</b> a. A contract will be developed that delineates the responsibilities of DPH staff, the audiology graduate students and the telemedicine center</p>	9/09	11/09	PM
<p><b>3. Pediatric Audiologists</b> a. Continue to maintain a list of pediatric audiologists willing to provide diagnostic evaluation to infants b. Include audiologists in south central region on list when equipment is purchased and they are ready to begin providing infant evaluations c. Include the Teleaudiology sites on list when the system is in place for infant diagnostic evaluations d. Develop sample fax-back form for Teleaudiology Project to use to share diagnostic results and other pertinent information with the</p>	9/09	3/11	PDEM & AA
	9/09	3/11	PDEM & AA
	11/09	03/11	PDEM & AA
	10/09	12/09	PC

child's medical home			
<b>3. Birthing/Neonatal Facility Newborn Hearing Screening Programs &amp; other facilities that provide hearing rescreens in these regions</b>			
<b>a.</b> Provide training to birthing facilities that are rescreening about the availability and referral process of pediatric audiology at the new site and the Teleaudiology Project	09/09	11/09	PM & PC
<b>b.</b> Meet with those birthing/neonatal facilities not doing rescreens about starting a rescreening program in conjunction with the new project.	09/09	10/09	PM & PC
<b>c.</b> Provide on-site technical assistance to these facilities as they begin rescreening programs	10/09	12/09	PM & PC
<b>d.</b> Develop sample script for facilities to use after an infant does not pass the rescreening, explaining the Teleaudiology Project	09/09	10/09	PC
<b>e.</b> Develop a sample form for facilities to use to notify primary care physician of infants not passing the rescreening within the Teleaudiology Project catchment area	10/09	10/09	PC
<b>4. Resources</b>			
<b>a.</b> Develop and disseminate educational materials for families, primary care providers, local health departments and others about diagnostic audiological evaluation using Teleaudiology Project	10/09	3/11	PM & PC
<b>b.</b> Develop and distribute physician education booklet, based on "World of Opportunity" booklet developed by Pennsylvania AAP	09/09	03/11	PM, PC & AA
<b>c.</b> Identify existing state resources where information about hearing screening and follow-up may be posted for public access	10/09	3/11	AA
<b>d.</b> Provide updated list of pediatric audiologists and information about Teleaudiology Project to state resource and referral lines (i.e. N.C. Family Health Resource Line, CARE-LINE, etc.)	11/09	3/11	PDEM
<b>5. Equipment</b>			
<b>a.</b> Purchase of infant diagnostic equipment for south central ENT practice	09/09	11/09	PC
<b>b.</b> Purchase of infant diagnostic equipment for Teleaudiology Project	09/09	11/09	PC
<b>6. Audiology training</b>			
<b>a.</b> Ensure that CHAC has appropriate training in use of equipment, diagnostic procedures and telemedicine terminology and techniques	10/10	10/10	PM
<b>b.</b> Ensure that audiologists at ENT practice in	10/10	10/10	PM

south central region have training in use of equipment, pediatric procedures and protocols for follow-up care and referrals			
<b>7. Diagnostic Services</b>			
a. Audiologists in ENT practice do infant audiological evaluations	12/09	3/11	PM
b. Ensure that all regional hospitals, rescreen facilities and physicians know about new diagnostic site	11/09	3/11	PC
c. Teleaudiology Project provides infant audiological evaluations	12/09	3/11	PM
<b>8. Data</b>			
a. Analyze data quarterly to ensure that referrals are being made to the ENT practice and the Teleaudiology Project	12/09	3/11	PDEM & AA
b. Generate reports for and disseminate to birthing facilities, audiologists, and the EHDI Advisory Committee quarterly	12/09	3/11	PDEM & AA
<b>9. Public Awareness</b>			
a. Develop flyers to inform the public about the Teleaudiology Project	01/10	03/10	PC
b. Explore methods of increasing public awareness of the need for prompt audiological evaluations for children who do not pass their newborn hearing screening	01/10	03/10	PC
<b>10. Family Support</b>			
a. Develop "Road Map" for families when their infant does not pass the initial hearing screening	09/09	12/09	PM & PC
b. Test "Road Map" with several families whose children refer on their initial hearing screening	01/10	01/10	PM
c. Modify "Road Map" based on parent feedback and distribute for use throughout state	02/10	03/11	PC
d. Identify and contact organizations in the participating regions that may provide support for families from various cultures	10/09	03/11	PM
e. Design prototype and purchase materials to assemble "Family Support Kits" for families whose children have hearing loss	10/09	01/10	PM & PC
f. Test, modify as needed and distribute kits	02/10	03/11	PC
<b>11. Cultural Competency Awareness</b>			
a. Identify resources for cultural competency and compile list	10/09	12/09	PC & AA
b. At each staff meeting, include time for discussion of cultural issues based on required cultural competency readings	12/09	03/11	PM



**Activities to Begin in Budget Period Two (April 1, 2010 – March 31, 2011)**

<b>Activities</b>	<b>Start Date</b>	<b>End Date</b>	<b>Responsible Staff</b>
<b>1. Birthing/Neonatal Facilities</b>			
<b>a.</b> Revise/update sample scripts about Teleaudiology Project for birthing facilities to use after an infant does not pass the rescreening based on feedback from facility staff	4/10	05/10	PC & AA
<b>b.</b> Revise/update information that hospitals give to parents of infants not passing the rescreening based on feedback from facility staff and Teleaudiology Project usage	4/10	05/10	PC & AA
<b>2. Health Care Providers</b>			
<b>a.</b> Revise/update educational materials for health care providers about diagnostic audiological evaluation of infants, and the services available in the south central and eastern regions	4/10	05/10	PC & AA
<b>b.</b> Investigate and test different methods of dissemination of materials to physicians and other health care providers for effectiveness	4/10	3/11	PM & PC
<b>c.</b> Identify primary care providers, including public health clinics and local health departments who would be willing to test effectiveness of teleaudiology being performed in their offices	09/10	12/10	PM
<b>3. Training and Technical Assistance</b>			
<b>a.</b> Continue providing technical assistance to all hospital rescreen personnel, local health departments, medical homes and others who need to understand the referral process.	04/10	10/10	PM & PC
<b>b.</b> Begin training and technical assistance for hospitals, health departments and other providers in the western part of the state who might have infants to refer to the Teleaudiology Project	10/10	03/11	PM & PC
<b>4. Public Awareness</b>			
<b>a.</b> Develop public awareness materials about expansion of Teleaudiology Project	10/10	11/10	PC & AA
<b>b.</b> Identify and/or develop public awareness materials about the importance of early diagnosis and intervention for children with hearing loss	10/09	3/11	PC & AA
<b>c.</b> Disseminate public awareness materials about new services and need for early diagnosis	12/10	03/10	PC & PM

<b>5. Sustainability</b> <b>a.</b> Analyze data quarterly to determine effectiveness of Teleaudiology Project <b>b.</b> Determine if Teleaudiology Project can be self supporting through billing for services <b>c.</b> Modify procedures and protocols to include expansion of project to remote sites in <b>d.</b> Develop and implement protocols for doing auditory evaluations in local health departments, physicians' offices and other appropriate sites.	04/10  09/10  11/10  12/10	03/11  02/11  12/10  01/11	PDEM & AA  PM  PM  PM, & AA
<b>7. Resources</b> <b>a.</b> Revise and update educational materials for families and health care providers about diagnostic audiological evaluation and the Teleaudiology Project <b>b.</b> Disseminate educational materials for families to local hospitals, health departments and medical homes about diagnostic audiological evaluation through teleaudiology	06/10  09/10	08/10  3/11	PC & PM  PC & AA
<b>8. Family Support</b> <b>a.</b> Meet with leaders from the medical community and the Native American community within Robeson County to discuss Teleaudiology Project <b>b.</b> Determine an appropriate site to do infant audiological evaluations via telemedicine <b>c.</b> Determine appropriate protocols for referral to this teleaudiology site <b>d.</b> Provide infant audiological evaluations at teleaudiology site	06/10  08/10  08/10  10/10	09/10  09/10  09/10  03/11	PM  PM  PM  PM

### Resolution of Challenges

The North Carolina Division of Public Health (DPH) has a longstanding commitment to promoting programs for young children and their families. The Early Hearing Detection and Intervention (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 loss to follow-up. The grant work plan will build on the strengths of ongoing EHDI efforts, anticipate known challenges, and document evolving concerns.

The Early Hearing Detection and Intervention (EHDI) Advisory Committee is an active group of stakeholders that examines needs and suggests solutions for implementation as well as contributing to long-range planning. Meetings in 2009-2011 will focus on loss to follow-up and how to address the challenges the proposed grant work plan will

encounter. Members of the committee will discuss the analysis of data from hospitals, review training materials and suggest strategies for promoting hospital networking.

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. Through ongoing technical assistance efforts, hospitals and providers are being educated about the importance of timely reporting.

Involvement of EHDI Program staff will address the challenges inherent in getting children referred for diagnostic evaluation promptly following re-screening in the regions involved in this project. On site technical assistance will be a strategy used to promote facilities doing their own re-screens. Hospitals will be asked to assist families by making the appointment for the diagnostic evaluation before the family leaves the re-screen appointment. All hospitals within the two regions will receive training in the procedures for referring to the new audiological site and the Teleaudiology Project. The EHDI Program Manager and Project Coordinator will assist with documenting requests for further training and ensuring the availability of personnel to support facility planning and implementation. Consultation documentation will identify what is working in the on-site model and what must be improved.

Documenting results of re-screen and diagnostic results are critical for reducing loss to follow-up. The EHDI program will continue to provide training on the WCSWeb Hearing Link to birthing/neonatal facility staff and audiologists. This training will expand beyond use of the data system to include emphasis on the importance of timely re-screening and diagnostic evaluations, the need for detailed documentation and the valuable role staff can have in reducing the loss to follow-up. The grant Administrative Assistant position will support better tracking and improved documentation.

The varied materials which are used by different facilities create a challenge. The grant work plan will identify/develop/distribute materials about the Teleaudiology Project and the new diagnostic location in the south central region, and encourage consistent use of these materials throughout the regions served by these projects. An additional challenge is obtaining written materials in languages other than English. Translation resources available through the Division of Public Health will be utilized. All materials will need to be culturally sensitive and family friendly. Care will be taken to provide materials useful for both staff and families.

The resources across the state are more concentrated in populated regions. When families live near the state border, they may go into the nearby states for services which makes follow-up difficult to document. Current economic conditions and high unemployment, coupled with the distance to resources and limited staff for home visits present challenges to providing individualized home-based family support. The supplement will pilot two different methods of making diagnostic resources more readily available to families.

The recognition of challenges is the key to designing effective change. This grant's approach is to provide avenues for obtaining access to diagnostic audiology services closer to home for families. The EHDI Program staff and Advisory Committee will assist with integrating efforts across the State.

### **Evaluation and Technical Support Capacity**

The North Carolina Early Hearing Detection and Intervention (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 serves as grant manager for the CDC Cooperative Agreement and is playing a vital role in designing and improving the hearing screening data capacity of WCSWeb Hearing Link. Working in conjunction with the computer programmers, this position is assuring a data system that will meet the needs of the program. Improvements planned for version 2.0 of WCSWeb Hearing Link will enable us to capture the specific data fields needed to 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) and to document a reduction in loss to follow-up. The Administrative Assistant position will work closely with the Evaluation Manager to develop and generate quarterly data reports for each birthing facility including a calculation of their loss to follow-up numbers. In addition, loss to follow-up data will be generated per each region in the state, which can be tracked for intervention and improvement.

WCSWeb Hearing Link will also be utilized to monitor the impact of the ENT office and telemedicine projects. Specific variables to be evaluated include age at diagnosis and numbers of children receiving diagnostic evaluation following a "refer" result on newborn hearing screening. The rate of change will be evaluated for each of these variables for the telemedicine project and for the ENT office project in the south central region of the state. Data managers in the Best Practices Unit will assist in identification of other "control" regions not served by these projects, but that have similar demographic variables. We will monitor rate of change in the served regions as compared to the "control" regions. Comparison of rates of change in the regions served by these projects to statewide data will also be made.

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 and service providers. 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.

Surveys will be developed, disseminated, and analyzed to address access to diagnostic audiology services in the regions served by the two projects in this supplement. This survey will address satisfaction with accessibility of diagnostic audiology services and barriers to services. Random sampling will be used and include families of infants who

- were identified as needing diagnostic evaluation after their newborn hearing screening that met the 1-3-6 goals and received diagnostic services in these regions prior to the initiation of this project,
- were identified as needing diagnostic evaluation after their newborn hearing screening that did not meet the 1-3-6 goals and received diagnostic services in these regions after the initiation of this project.

### **Organizational Information**

North Carolina's Early Hearing Detection and Intervention (EHDI) Program is organizationally located within North Carolina Department of Health and Human Services, Division of Public Health (DPH). It is housed in the Women's and Children's Health Section, Children and Youth (C&Y) Branch. The Women's and Children's Health Section Chief serves as the North Carolina 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. Federal Maternal and Child Health Bureau priorities are established in the following order from highest to lowest: 1) Infrastructure building, 2) Population based services, 3) Enabling services, and 4) Direct services.

The primary purpose of the C&Y Branch 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, with several additional programs that focus specifically on adults. 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.

In 2006, The C&Y Branch convened a Health Disparities Work Group. Based on the Work Group recommendations, the Branch: 1) is conducting both a Branch-level organizational and individual self-assessments (offered to staff) on cultural and linguistic competence, 2) has revised the Branch Logic Model to incorporate health disparities and cultural and linguistic competence in Branch and Division level objectives, 3) has developed and maintains a reference list and a resource library related to health disparities, cultural and linguistic competence, and specific cultural groups or populations in North Carolina, including those with disabilities and those with low literacy skills, 4) maintains and continues to expand external relationships (i.e. committees, agencies, organizations, groups, individuals) focused on health disparities, cultural and linguistic

competence and specific minority groups, and 5) supports staff development opportunities related to these topics.

The Branch has also established an on-going Eliminating Health Disparities (EHD) Work Group. The group's mission is to promote and advocate for the elimination of health disparities among all racial/ethnic populations, persons with disabilities, and other underserved populations ages birth to 21. The Work Group meets quarterly and its objectives are directed by a C&Y Branch EHD strategic plan which is updated annually. An example of one of the EHD Work Group programs is the development and distribution of a monthly Minority Outreach Newsletter. This newsletter is written by our C & Y Minority Outreach Coordinator to educate staff about the diverse populations served in North Carolina. Lunch discussions, speakers and informal gatherings are also offered to the staff to increase awareness and knowledge about the diverse social, cultural and language of the people living in our state.

The C&Y Branch is composed of the following Units: Best Practices Unit, Genetics and Newborn Screening Unit, Health and Wellness Unit, Operations Unit, School Health Unit, and Specialized Services Unit. All of the units incorporate the themes of Children and Youth with Special Health Care Needs, Transition, Medical Home, Eliminating Health Disparities, Cultural Competency and Implementation of Evidence-Based Practices. Programs in all units address access to care and have services and initiatives that focus on availability, accessibility and utilization of primary and preventive health (and related) services for children and youth. These programs provide infrastructure development, clinical guidance, quality assurance, technical assistance, consultation, and training for professionals who provide children's services in the state. In some instances, programs also provide direct care to the populations served.

Because the array of programs cover such a broad spectrum of care, interagency collaboration is a key component of service development and implementation resulting in strong partnerships with the Division of Medical Assistance, Division of Mental Health/Developmental Disabilities/ Substance Abuse Services, Division of Social Services, More at Four, Office of Education, Division of Child Development, Office of Research, Demonstrations and Rural Health Development, Division of Facility Services, State Employees Health Plan, Department of Environment and Natural Resources, Department of Public Instruction, and state and private medical schools and universities. In addition to state partnerships, formalized collaborative planning occurs with families/parents, NC Partnership for Children, children's advocacy groups, public, private not-for-profit and some for-profit organizations that serve children. Special emphasis is placed on continuous and strong interactions with all levels of private providers for children's services.

The Early Hearing Detection and Intervention (EHDI) Program located within the Genetics and Newborn Screening Unit consists of a Program Manager who functions as North Carolina's EHDI Coordinator and provides leadership to North Carolina's EHDI Team; 12 regional child health consultants; a Project Coordinator who oversees HRSA UNHS grant initiatives; a Program Development and Evaluation Manager who provides

leadership with data development; a Administrative Assistant, supported by HRSA funds who coordinates the childhood hearing health surveillance activities using WCSWeb Hearing Link, 2 data specialists, and a support staff.

The regional child health consultants include six DPH speech language consultants, two of whom are employed in the Genetics and Newborn Screening Unit. The other four are contract employees (two are full-time and two are part-time) through local developmental disabilities or health department agencies. Currently, each of these speech language consultants provide: 1) technical assistance, training, and consultation to birthing facilities on best practices for running a newborn hearing screening program, 2) technical assistance, training, and consultation to families, hospital staff, and other providers on normative communication development, 2) support and assistance to families in identifying and accessing appropriate screening and diagnostic services, 3) Hearing Link training to birthing facilities, 4) tracking of children who miss their newborn hearing screen or who need a re-screen, 5) when necessary, initial hearing screenings and re-screens for families who do not have access to other services, and 6) educational programs for community groups and agencies regarding newborn hearing screening, language development and communication related issues. The speech language consultants are also responsible for visiting the birthing facilities on a quarterly basis to review hospital performance to assure that key components are in place for a successful local program.

There are four full-time DPH audiology consultants employed in the Genetics and Newborn Screening Unit. The other two are contract employees (one is full-time and one is part-time) through a local developmental disability agency and health department. Currently, each of these audiology consultants provide: 1) habilitation consultation to families and providers following diagnosis of hearing loss, 2) training and consultation to pediatric audiologists, physicians, other child service provider agencies on the newborn screening process as well as on recommended practices in diagnosis of hearing loss and amplification fitting, 3) tracking of children who have been identified as possibly having a hearing loss from diagnosis through early intervention services, 4) monitoring of children who have been diagnosed with a hearing loss from birth to age 21, 5) yearly health department hearing screening trainings, 6) Hearing Link trainings for hospitals and pediatric audiologists, 7) in-services to head start programs, early intervention programs and physicians as well as educational programs for community groups and agencies regarding hearing related issues, and 7) some clinical services including ear molds and other audiologic services as requested.

WCSWeb was developed in collaboration with the State Laboratory of Public Health (SLPH) and with the Sickle Cell Program located in the Women's and Children's Health Section of DPH. The Hearing Link and Sickle Cell modules were implemented in 2006. Data submitted to the State Laboratory is entered into the Laboratory Information Management System (LIMS) which shares information with WCSWeb. The Children and Youth Branch (C&Y) continues to discuss the need for an integrated child health data system with the Immunization Branch in DPH who has developed a web-based immunization registry and with the Vital Records Unit who has plans to implement an

electronic birth certificate. These activities are included in the CDC Cooperative Agreement.

Input and feedback for North Carolina's Early Hearing Detection and Intervention Program planning, implementation, and evaluation are provided through the Program's Advisory Committee. In addition, input and feedback are provided from the Women's and Children's Health Section Family Advisory Council for Children with Special Needs, and the Governor's Commission for Children with Special Health Care Needs.

The North Carolina General Assembly passed legislation establishing the North Carolina UNHS Program in October 1999 requiring that "the Department of Health and Human Services...establish and administer a Newborn Screening Program. 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)]

The General Assembly gave authority to the Commission for Health Services to adopt rules regulating the implementation of the Newborn Hearing Screening Program. Those rules were updated in August 2004 and require:

1. Medical facilities that provide birthing or inpatient neonatal services to physiologically screen each newborn in each ear for the presence of permanent hearing loss before the infant is discharged from the medical facility after birth unless medical complications prevent such; and
2. Maintain the equipment necessary to physiologically screen each newborn for the presence of permanent hearing loss.
3. Any physician that attends a newborn within 30 days of birth and determines that the newborn has not been physiologically screened in each ear for the presence of permanent hearing loss shall refer the patient for such screening within 30 days of birth or as soon as is practical.
4. Parents or guardians may object to the hearing screening.
5. When an attending physician has issued an order that diagnostic auditory evoked response testing be performed for an infant who exhibits medically recognized risk factors of auditory deficits, a hearing screening is not required to be performed on the infant. The outcome of the diagnostic testing procedures shall be reported.

Reporting requirements were updated in April 2003 and require:

1. All persons performing physiologic hearing screenings for infants less than six months of age to report within five days following the screening (or date of the appointment for the screening) to the North Carolina State Laboratory of Public Health, using forms developed by the Department of Health and Human Services:
2. All persons performing diagnostic auditory evaluations and assessments for selection of amplification for infants less than twelve months of age shall report within five days of the appointment to the North Carolina State Laboratory of Public Health, using forms developed by the Department of Health and Human Services.



