

Project Narrative

Background

Legislation establishing North Carolina's Early Hearing Detection and Intervention (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). Copies of the legislation and administrative rules may be found in the appendices. From the beginning, the Program had 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.

Due to the longstanding relationship between birthing facilities and the North Carolina State Laboratory of Public Health (SLPH) regarding Newborn Screening (NBS) and the presence of an existing data system at the SLPH which included information on all births, the decision was made for newborn hearing screening results to be reported to the SLPH on the Newborn Screening (NBS) form. Data processing staff at the state lab then manually entered the demographic and hearing screening information into their data system, Laboratory Information Management System (LIMS). This process did not allow for timely data analysis by the EHDI Program and individual identifiable data was difficult to obtain. Responsibility for tracking and surveillance activities was originally assigned to regional speech language and audiology consultants. However, the amount of time and travel required for those staff members to carry out their consulting duties and delays in receiving data from LIMS limited their ability to

effectively and efficiently track individual children throughout the EHDI process. This led to many children being lost to follow-up, or more accurately described, lost to documentation.

Development of Women's and Children's Section Web (WCSWeb) version 1.0 began in 2001 as a collaborative effort between the EHDI Program and the SLPH. WCSWeb is a web-based data tracking and surveillance system developed and utilized by both the EHDI Program and the Sickle Cell Program within the Division of Public Health (DPH). The EHDI part of this system is referred to as "Hearing Link", while the Sickle Cell portion is referred to as "SCell". Both parts of this system received electronic transfer of data from the SPLH data system (LIMS). This project was designed to create a unique web-based tracking and surveillance system which would allow for direct data entry and tracking by providers throughout North Carolina.

Throughout the remainder of this proposal, the data system will be referred to as "Hearing Link".

Many delays were experienced during the development of the initial version of Hearing Link including: (1) difficulty determining the state agency whose server would host the application, (2) short-term or delayed execution of contracts for computer programmers, (3) inadequate understanding of capabilities and restraints of computerized tracking by EHDI staff assigned to work in conjunction with the programmers, (4) difficulties developing systems and procedures that were mutually beneficial for both the SLPH and the EHDI Program, and (5) inadequate quality assurance testing of the application prior to deployment. These roadblocks delayed the implementation of a pilot project with six birthing facilities for more than two years.

Several steps were taken by the Program to address the delays and find solutions that would allow the project to move forward. The current computer programmer began work on this project in September 2004 and an audiologist with in-depth understanding of computer capabilities and systems design was transitioned into the role of liaison between the EHDI

Program and Information Technology Services (ITS) beginning in October 2005. This audiologist was permanently re-assigned to the role of Program Development and Evaluation Manager in December 2006. Through these efforts, the system that is currently in use was developed.

These staff changes, coupled with feedback obtained from the six pilot facilities, led to a re-design of Hearing Link to include direct data entry from birthing facilities and/or 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, and (6) information regarding follow-up appointments. Demographic information may be edited when needed, to reflect updated name, address, phone, or primary care physician information. The name of the facility may also be updated for babies who transfer from the birthing facility to a neonatal intensive care unit (NICU) at another hospital, in order to facilitate tracking and surveillance activities. Additionally, labels may be printed for the Newborn Screening form. In collaboration with the State Lab and birthing facilities, fields for feeding type and other information necessary for timely processing of metabolic screening have been required. Labels may not be printed with missing information in those fields. This requirement has reduced the number of metabolic screening samples being deemed unsatisfactory by the State Lab due to missing information; thereby, reducing the number of babies undergoing repeat heel sticks. By placing the responsibility for direct data entry of demographic, hearing screening, and metabolic screening information into Hearing Link onto the birthing facilities, those facilities are able to know immediately when hearing screening results are not reported. This eliminates the 1-3 week delay previously experienced by the EHDI Program waiting for demographic records to be electronically transferred from the LIMS system

at the SLPH. Due to this delay, birthing facilities could not be contacted by Program staff until long after the infant had been discharged.

In order to allow meaningful data analysis to occur, it was determined that archived data should be electronically transferred into Hearing Link from LIMS. In June 2006, demographic and hearing screening data for all babies born on or after January 1, 2004 was successfully transferred into Hearing Link.

Implementation of Hearing Link with birthing facilities and audiologists throughout the state began in September 2006. In-depth training for regional EHDI Program staff was the first step toward widespread implementation of the data system. Staff needed a complete understanding of the system in order to effectively provide training for hospital personnel, audiologists, and other service providers about how to utilize the data system. Following this training, and development of a detailed training script and competency checklist, all but the newest EHDI Program staff member, who has less than six months experience in the Program, is able to train others to use Hearing Link.

A user's manual was developed to accompany the web-based system. The specific content to be included in the manual for each user is determined by the level of accessibility assigned to the user. This manual is in notebook format, so pages can be replaced or added when policies or systems change.

Currently, all of North Carolina's 89 birthing/neonatal facilities offer initial newborn hearing screening services prior to infant discharge from the facility and 98.2% of infants born in North Carolina in 2006 were screened for the presence of permanent hearing loss. The Program provides tracking and surveillance for infants through the screen-rescreen-diagnosis-amplification process utilizing Hearing Link (v 1.0). Presently, 28 of the 89 birthing facilities

and 125 audiologists in North Carolina have been trained to use the system. These 28 birthing facilities accounted for 45% of the occurrent births in North Carolina during 2006. We have found that hospitals receiving initial Hearing Link training directly from the EHDI Program staff, and structured in-person follow-up visits following the training, use the Hearing Link with significantly better success. This has resulted in the gradual roll out of the Hearing Link across the state with the systematic training of additional hospitals over several years.

In an effort to address the need to have centralized staff whose primary responsibility is tracking and surveillance, two full-time tracking and surveillance assistant positions have been created and approval has been obtained for one full-time surveillance specialist. These three positions provide tracking and surveillance for 70 of the 100 counties in North Carolina.

The analysis of Hearing Link data has identified several challenges which need to be addressed in future versions of Hearing Link, including: (1) over-duplication of patient data, (2) under-reporting of re-screening and/or diagnostic evaluations for infants suspected to have a hearing loss, (3) under-reporting of amplification fitting for children with diagnosed hearing loss, (4) lack of referral, eligibility and enrollment data regarding early intervention services, and (5) lack of data sharing agreements with EHDI programs in other states. Program and birthing facility staff identified 3,038 infants born in 2006 with duplicate patient records in Hearing Link. Many of the duplicate records resulted from infants who had inaccurate or incomplete information entered into the LIMS system, which was subsequently transferred into Hearing Link. The data entered into LIMS originates from hand-written forms, which leads to errors due to poor penmanship, misspelling, or missing information.

The on-going analysis of data will be utilized in the continued development of future versions of Hearing Link. Computer programming for maintenance of the current application and

development of future versions will be provided by DPH Information Technology Services. Funding, through this Cooperative Agreement, for a 1.0 FTE surveillance quality monitor will be required for full implementation of the quality assurance and improvement plan. Funding is also required, through this Agreement, for a 1.0 FTE surveillance specialist. The addition of these two grant-funded staff members will allow completion of the transition to centralized data tracking and surveillance for all North Carolina occurrent births.

Work Plan

The new Cooperative Agreement proposed in this document will allow North Carolina to fully implement WCSWeb – Hearing Link throughout the State, provide necessary enhancements to the data system, fully transition to centralized data tracking and surveillance, improve reporting of results at each stage of the EHDI process, and develop and implement a quality assurance and improvement plan to monitor the accuracy and quality of data reported to the Program. Through these efforts, North Carolina will be able to assure timely follow-up and minimize loss to follow-up or loss to documentation.

In accordance with grant guidance, the goals of this grant are to (1) enhance Hearing Link to accurately identify, match, and collect unduplicated individual identifiable data, (2) enhance the capacity of Hearing Link and the EHDI Program to accurately report the status of every occurrent birth throughout the EHDI process for the purpose of evaluating progress toward National EHDI goals, and (3) develop and enhance the capacity to integrate Hearing Link with other state tracking and surveillance programs that identify children with special health care needs. Goals and objectives were developed with input from the EHDI Advisory Committee, which consists of key stakeholders in the EHDI process, feedback from users of Hearing Link, and review of a quarterly sampling of data since January 2006.

Through funding provided in this Cooperative Agreement proposal, the following benefits are expected: (1) an increase in use of Hearing Link for data entry, tracking, and surveillance, (2) more timely and easily generated reports to ensure better monitoring of children and their needs, resulting in fewer children lost to follow-up, (3) increased amounts of reliable data available for each stage of the EHDI process, and (4) collaborative activities among agencies responsible for children with special health care needs to facilitate seamless service delivery to children and their families.

The activities of this Cooperative Agreement will help the EHDI Program in North Carolina build on the success of the existing tracking and surveillance system, Hearing Link (v 1.0). The grant activities will take place over a period of three years, beginning July 2008. A Gantt chart is provided in the appendices.

The Children and Youth Branch, through the Branch Management Team, will address sustainability and on-going success of the project through regularly scheduled meetings. Meeting notes will reflect plans and discussions to address sustainability.

Goals and Objectives

Goal 1: To enhance the capacity of WCSWeb – Hearing Link to accurately identify, match, and collect unduplicated individual identifiable data.

Objective 1: *By January 2009, Hearing Link will include a “name alert” for users when potential duplicate entries exist within the data system.* This alert will include notification to users of Hearing Link while they are in the process of adding a “new patient” record, by making HIPPA compliant information visible to the user on the computer screen. The following demographic variables will be considered in the identification and matching of duplicate records:

(1) baby's last name, (2) mother's first and last name, (3) baby's date and time of birth, (4) baby's medical record number, and/or (5) home address.

Objective 2: *By June 2009, a data quality assurance plan will be developed.* This plan will include provisions for chart reviews in birthing facilities and offices of other providers.

Objective 3: *By June 2009, Hearing Link will generate a back-up report of potential duplicate entries, including records manually entered by users and records electronically transferred from other data systems, daily.* This report will consider the same demographic variables outlined in Objective 1. Tracking and surveillance staff will utilize this report when matching duplicate records.

Objective 4: *By December 2009, a data quality assurance plan will be implemented.*

Implementation of this plan will involve stakeholders, EHDI Program staff, centrally located tracking and surveillance staff, and other collaborative partners.

Activities associated with Goal 1 will include database redesign, user interface programming, quality assurance testing, deployment of new code to production, hiring of grant funded staff, development of quality assurance and improvement plan, and implementation of chart reviews and other data analysis methods.

Staff with primary responsibility for these activities will be the computer programmer from Information Technology Services (ITS) and the Program Development and Evaluation Manager from the Genetics and Newborn Screening Unit. Additional staff/partners required for implementation of Goal 1 include surveillance specialists, surveillance quality monitor, tracking and surveillance assistants, and the EHDI Advisory Committee.

Goal 2: To enhance the capacity of Hearing Link and the EHDI Program to accurately report the status of every occurrent birth throughout the EHDI process for the purpose of evaluating progress toward National EHDI goals.

Objective 1: *By December 2008, EHDI speech language and audiology consultants will utilize data analysis to provide targeted consultation for specific agencies and/or providers in order to correct any systemic or best practice issues that are detrimental to meeting Program goals.*

Objective 2: *By June 2009, Hearing Link will be modified to accurately document/report the number/percentage of infants who passed/did not pass the initial newborn hearing screening and the number/percentage of infants who pass/did not pass the final newborn hearing screening.*

Objective 3: *By June 2009, Hearing Link will be modified to accurately document/report the number/percentage of infants referred for and/or completing diagnostic audiologic evaluations following failed newborn hearing screening.*

Objective 4: *By June 2009, tracking and surveillance for 100% of North Carolina's occurrent births will be transitioned to centralized data tracking process.*

Objective 5: *By June 2009, hearing screening status (including documentation of families who decline the screening or infants who are deceased) will be known for 99% of infants prior to the age of 1 month, excluding infants more than 1 month of age who have not been discharged from a NICU.*

Objective 6: *By July 2009, Hearing Link will be implemented in 100% of birthing facilities in North Carolina.*

Objective 7: *By December 2009, diagnostic audiology evaluation status (including documentation of families who decline the evaluation or infants who are deceased) will be*

known for 80% of infants who did not pass the newborn hearing screening prior to the age of 3 months, excluding infants who have not been discharged from a NICU.

Objective 8: *By June 2010, Hearing Link will be modified to accurately document/report the number/percentage of infants referred for and enrolled in early intervention services, to include eligibility determination for Part C services.*

Objective 9: *By June 2010, amplification fitting status (including documentation of families who decline the fitting or infants who are deceased) will be known for 90% of infants, for whom amplification was recommended prior to the age of 6 months, excluding infants who have not been discharged from a NICU.*

Objective 10: *By June 2011, Hearing Link will be modified to accurately document/report the number/percentage of infants referred for and/or completing diagnostic audiologic evaluations following passed newborn hearing screening (late-onset or progressive hearing loss).*

Objective 11: *By June 2011, early intervention status (including documentation of families who decline services or infants who are deceased) will be known for 90% of infants with diagnosed hearing loss prior to the age of 6 months, excluding infants who have not been discharged from a NICU.*

Activities for Goal 2 will include (1) hiring of grant funded staff, (2) database redesign, user interface programming, quality assurance testing, and deployment of new code to production, (3) planning with early intervention service agencies on collaborative data reporting, (4) development and implementation of child-specific data sharing agreements, (5) revision of administrative rules, (6) generation of quarterly data reports, (7) development of birthing facility program plans for newborn hearing screening to include data reporting, and (8) development and implementation of targeted consultation procedures.

Staff with primary responsibility for these activities will be the Program Development and Evaluation Manager, ITS computer programmer, EHDI Program Manager, and Genetics and Newborn Screening Unit Manager. Additional staff who will participate in the implementation of Goal 2 are the surveillance specialists, surveillance quality monitor, tracking and surveillance assistants, and regional speech language and audiology consultants. Activities will involve collaborative participation from Part C Early Intervention, Office of Education Services, BEGINNINGS for Parents of Children Who are Deaf or Hard of Hearing, the EHDI Advisory Committee, and birthing/neonatal facilities.

Goal 3: To develop and enhance the capacity to integrate Hearing Link with other state tracking and surveillance programs that identify children with special health needs.

Objective 1: By December 2008, convene a committee who will recommend procedures for sharing child-specific information across programs and agencies. This committee would initially focus on (a) reciprocal referral, (b) identification of unexpected clusters of infants with hearing loss in particular regions and particular times, (c) subsequent risk for children with permanent hearing loss, and (d) unexpected differences in screening performance on key variables such as birthing facility, racial/ethnic characteristics, gender, geographic location, false positive rates, loss to follow-up rates, and developmental indicators (e.g. language scores, socio-emotional levels, and/or achievement scores).

Objective 2: By June 2011, develop and implement reciprocal data sharing agreements with EHDI programs in other states and territories. This plan will aim to include all states and territories, not just “border states”, due to North Carolina’s large military population.

Activities for Goal 3 will include formation of an inter-agency data sharing committee and establishment of communication with EHDI programs in other states.

Staff with primary responsibility for these activities will be the Program Development and Evaluation Manager and the EHDI Program Manager. Activities will involve collaborative participation from EHDI programs in other states/territories, Part C Early Intervention, Office of Education Services, BEGINNINGS, and the EHDI Advisory Committee

Collaborative Efforts

The North Carolina EHDI Program 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 systems change. Within the Division of Public Health (DPH), collaborative partners include the North Carolina State Laboratory of Public Health (SLPH) and the Women's and Children's Health Section (WCHS) Sickle Cell Program. On-going computer programming and maintenance support is provided through Information Technology Services (ITS). Other partners include birthing/neonatal facilities that perform initial newborn hearing screening, audiologists performing diagnostic evaluations and hearing aid fittings for young children, BEGINNINGS For Parents of Children Who Are Deaf or Hard of Hearing, Office of Education Services (OES), Part C Early Intervention (EI), and the EHDI Advisory Committee.

The EHDI and Sickle Cell Programs have worked together to provide the program-specific requirements and the funding necessary for development and maintenance of WCSWeb (Hearing Link and SCell portions), and for preliminary development of WCSWeb (v. 2.0). A Working Agreement between the EHDI Program and the Sickle Cell Program is attached in the appendices.

The SLPH has collaborated extensively with the EHDI and Sickle Cell Programs to establish and maintain a mutually beneficial process for data sharing, integration and linkage of their data

system – Laboratory Information Management Systems (LIMS) with WCSWeb. For those hospitals in which Hearing Link has been implemented, demographic data for each live birth is entered directly into the data system by hospital staff. Printed labels with the information required for newborn metabolic screening forms may then be generated. This process allows for fewer errors due to unclear handwriting or incomplete information on the metabolic screening forms. In hospitals where Hearing Link has not yet been implemented, the newborn metabolic screening forms continue to be filled out by hand, including the results of hearing screening. The demographic information and hearing screening results are then manually entered into LIMS by state lab data entry staff, and the information is electronically transferred to Hearing Link. This process requires open communication and cooperation on a regular basis to address issues that may arise due to the needs of each agency’s surveillance system. This communication has allowed both agencies to provide better tracking and surveillance. Due to a significant number of home births, the collaboration with the SLPH will need to continue to assure that all occurrent births are captured within Hearing Link. The North Carolina State Laboratory of Public Health and the North Carolina EHDI Program have a Working Agreement, which is included in the appendices.

Information Technology Services (ITS) collaborates with all agencies within DPH. The purpose of ITS is to provide on-going computer programming and maintenance support for data systems throughout the Division, so a Working Agreement is not warranted.

Twenty-eight of North Carolina’s 89 birthing facilities are currently using the Hearing Link. While reporting of hearing screening results is required by administrative rule, utilizing Hearing Link is not. Hospitals have agreed to collaborate because of the advantages of using printed labels and the increased ease of tracking infants screened for hearing loss in their facility. As

more hospitals begin to do their own outpatient hearing re-screens, they are increasingly aware of the usefulness of Hearing Link as a tool to track those infants who need to return for screening or follow-up.

North Carolina currently has 17 audiology practices, with varying numbers of audiologists per practice, who can complete infant diagnostic audiology evaluations.

The EHDI Program maintains a list of infant audiology practices on the web site www.ncnewbornhearing.org who, by self-report, have met the criteria established by the EHDI Advisory Committee in 2006 for completion of infant diagnostic audiology evaluations. In conjunction with South Carolina in March 2008, the National Center for Hearing Assessment and Management (NCHAM) provided intensive pediatric audiology training in Charlotte, NC. The EHDI Program provided funding for 19 North Carolina audiologists to attend this workshop, which enhanced state-wide capacity to provide high quality, evidence-based pediatric audiology services.

Audiologists throughout North Carolina who are involved in diagnosing or fitting amplification for children collaborate with the Program by using Hearing Link to enter diagnostic results or amplification data. Reporting audiological results for children up to one year of age is required by administrative rule. Many audiologists are using Hearing Link to report results for children of all ages. Those who do not choose to enter the data via Hearing Link are able to complete the North Carolina Early Hearing Detection and Intervention Program Diagnostic/Amplification Reporting Form, and the information is entered into the data system by EHDI tracking and surveillance staff. EHDI Program audiology consultants will continue to provide technical assistance and training to these audiologists regarding data reporting and best practices.

Referral to intervention services is recommended for any child in North Carolina who is diagnosed with a hearing loss. There are several avenues to make these referrals. Referrals may be made to BEGINNINGS, a North Carolina advocacy and family support organization. Providers may also refer to North Carolina Early Intervention for Children who are Deaf or Hard of Hearing, a program provided through the OES. Another option is to refer to the Part C EI Program. All three of these agencies collaborate to provide data on children who are deaf or hard of hearing.

BEGINNINGS provides Child Find information to the EHDI Program and both early intervention programs for all children (0 – 3 years of age) for whom they receive a referral. This information is distributed to the other three agencies on a bi-weekly basis. BEGINNINGS also shares aggregate data on the number of referrals, age of identification and geographic distribution of the children. Further, BEGINNINGS provides Child Find information to the EHDI Program for children 3-21 years of age for whom they receive a referral, also on a bi-weekly basis. A Working Agreement between BEGINNINGS and the EHDI Program is attached in the appendices.

In addition to providing data, the OES collaborates with the EHDI Program by funding a 0.5 FTE audiology consultant. This regional consultant is responsible for tracking children within the region who have been identified with a hearing loss from diagnosis through early intervention. The consultant is also involved in providing training and technical support to hospitals, audiologists and other service providers who are using Hearing Link. Additional OES staff collaborate with EHDI Program regional consultants to make home visits with families of children with hearing loss and insure that all available resources have been explained and offered

to the family. Also included in the appendices is the Working Agreement between the EHDI Program and the OES.

Part C EI is coordinated in North Carolina through the Division of Public Health. The EI Program consists of 18 Children’s Developmental Services Agencies (CDSAs) throughout the state, some of which are contractual service providers. Aggregate data concerning the number of children with hearing loss enrolled in Part C EI has been provided to the EHDI Program. However, the Part C EI Program has reported that this data is incomplete due to limitations of their current data system. Strategies for sharing child specific information are in development. The Working Agreement between EI and the EHDI Program is in the appendices.

Collaboration efforts would not be complete without input from the wide variety of stakeholders in the EHDI process. The EHDI Advisory Committee includes representation from most of the entities involved in this process and has provided leadership and direction for all aspects of the EHDI Program, including data management and surveillance. In addition to the agencies described above, Committee membership represent families, hospitals, physicians, the NC Division of Services for the Deaf and Hard of Hearing, the Department of Public Instruction, audiologists, and university educators involved in the training of speech language pathologists and audiologists. A list of Advisory Committee members is provided in the appendices. Each member provides his/her time and expertise to this collaborative effort for the development of a comprehensive and coordinated EHDI Program.

Program Capacity

The North Carolina Early Hearing Detection and Intervention (EHDI) Program established in 1999 is organizationally located in the 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 (WCHS), Children and Youth Branch (C&Y), in the Genetics and Newborn Screening Unit which also includes the DPH Metabolic Screening Follow-up Program. The WCHS 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. The C&Y Branch Head is the Title V State Director for Children with 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 EHDI Program 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 EHDI Program is administered by staff in the Genetics and Newborn Screening Unit, which includes a Unit Manager, a Program Manager (EHDI Coordinator), a Program Development and Evaluation Manager, a Project Coordinator, 12 regional speech-language pathology and audiology consultants, and three centrally located tracking and surveillance staff.

The Women's and Children's Section Web (WCSWeb) was developed in collaboration with the State Laboratory of Public Health (SLPH) and the Sickle Cell Program within DPH. The Sickle Cell Program is organizationally housed in the WCHS, in the Women's Health Branch (WH).

The Early Hearing Detection and Intervention (EHDI) Advisory Committee, established in 2001, is an active group of stakeholders that examines needs and suggests solutions for implementation as well as contributing to long-range planning. Input and feedback are also

provided to the EHDI Program through the WCHS Family Advisory Council for Children with Special Needs, and the Governor's Commission for Children with Special Health Care Needs.

There are currently 89 birthing/neonatal facilities in the state. These centers account for 99.5% of occurrent births (2006 Hearing Link data) and all perform initial newborn hearing screening services prior to infant discharge from the facility. North Carolina legislation mandates that newborn hearing screening results and metabolic screening be reported to the State Laboratory of Public Health. Providers are required to report hearing screening results for children up to 6 months of age and are required to report diagnostic evaluation and/or amplification fitting results for children up to 12 months of age. Due to the reporting association with metabolic screening, a designated primary care physician is reported for each child. In the year 2006, 97.2% of children born had a medical home reported (2006 Hearing Link data)? Collaboration with medical homes is addressed within multiple projects throughout the Women's and Children's Health Section (WCHS).

The North Carolina Early Intervention Infant-Toddler Program (EI) also resides in the WCHS. The C&Y Branch and EI Branch maintain a close relationship to assist in clarification of the mutual needs and responsibilities for providing services to young children identified with hearing loss.

The North Carolina Office of Education Services' (OES) Early Intervention for Children who are Deaf or Hard of Hearing Program provides services to children ages birth to three years who are deaf, hard of hearing, or deaf/blind and their families. Concentrating on language and communication skill development, itinerant professionals provide family-centered intervention in home and daycare settings. At age three, the program works to establish a smooth transition to the local education agency.

Information Technology Services (ITS) is a state-wide agency. The purpose of ITS is to provide on-going computer programming and maintenance support for data systems throughout the State.

All of the eighty-five local health departments and districts (LHD) across the state provide health promotion, prevention of disease, and protection of NC populations and environment. During the past several years, all LHDs have received otoacoustic emission (OAE) hearing screeners from the EHDI Program for use during well baby health checks. Annual training and on-going support are provided to LHD staff in proper use of OAEs by EHDI Program audiology consultants. In addition, combination tympanometers/audiometers have been purchased for the LHDs by the EHDI Program. Training is ongoing to ensure proper use of this equipment as well.

Currently, there are family-to-family support groups related to children with hearing loss in four metropolitan areas of the State. Parent educators with Beginnings for Parents of Children Who are Deaf or Hard of Hearing, teachers with the OES 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.

Staffing and Management Plan

The Principal Investigator/Project Director for this application is the Program Development and Evaluation Manager, Marcia Fort, Au.D., CCC-A. Dr. Fort is an audiologist who was permanently re-assigned in December 2006 to provide continued development and implementation of WCSWeb, provide data analysis and reports, coordinate quality assurance activities, develop and maintain a centralized data tracking plan, and provide technical assistance to birthing centers and providers regarding data reporting procedures and use of the Hearing Link

portion of the system. Dr. Fort is the liaison between the EHDI Program and agencies housing other data sources which are, or will be, integrated with WCSWeb. Dr. Fort manages the centralized data tracking staff, provides programmatic management for the Information Technology Services staff assigned to WCSWeb, and functions as the data manager for the EHDI Program. Her previous work has focused on audiology program development and management, clinical services, and outreach efforts (training and consultation). Dr. Fort will spend 80% of her time on activities related to this proposal.

The Genetics and Newborn Screening Unit Manager is Joan Crissey, M.A., CCC-SLP. Ms. Crissey is a speech language pathologist whose work has focused on clinical services, program evaluation, training, consultation, and outreach efforts. She was named EHDI Program Manager in December 2004, and assumed the unit manager position in July 2005, where she has overall supervisory responsibility for approximately 26 Unit staff including program managers, clinical consultants and administrative personnel. Ms. Crissey has primary responsibility for program budgets, policy development and interpretation, contracted services, personnel actions, and program development, liaison and negotiations. Unit programs include Early Hearing Detection and Intervention, Metabolic Screening and Genetics Services.

The EHDI Program Manager is Kathleen Watts. Ms. Watts has a Master's degree in Public Health Education and previously worked as the Director of Training and Technical Assistance for the National Center for Hearing Assessment and Management (NCHAM). Ms. Watts joined the North Carolina EHDI Program in February 2007 and has primary responsibility for the EHDI Program, providing leadership to North Carolina's regional EHDI consultants. Ms. Watts will spend 30% of her time on activities related to this proposal.

Tracking and surveillance assistants (2.0 FTE) currently provide data entry, tracking and surveillance for 45 of the 100 counties in North Carolina, each spending 100% of their time on activities related to this proposal. DPH has received funding through a HRSA Universal Newborn Hearing Screening grant for a 1.0 FTE surveillance specialist, who will provide coordination of centralized tracking activities, data tracking for an additional 25 counties, and assist the Program Development and Evaluation Manager with technical assistance for providers using Hearing Link. It is anticipated that this position will be filled by June 1, 2008 and will spend 100% of his/her time on activities related to this proposal.

There are 5.0 FTE regional EHDI Program speech language consultants, two of whom are employed full-time in the Genetics and Newborn Screening Unit. The others are contract employees (two part-time and two full-time) through local developmental disabilities or health department agencies. Each speech language consultant is responsible for: 1) participating in tracking of children who miss their newborn hearing screen, who need a rescreen, or who need a diagnostic audiologic evaluation, 2) providing technical assistance, training, and consultation to families, hospital staff, and other providers on normative communication development, and 3) reviewing hospital performance to assure that key components are in place for a successful local newborn hearing screening program. Each of these six staff members will spend 25% of their time on activities related to this proposal.

There are 5.5 FTE regional EHDI Program audiology consultants, four of whom are employed full-time in the Genetics and Newborn Screening Unit. One is a full-time contract employee and the other 0.5 FTE serves through a collaborative effort with the Office of Education Services. Each audiology consultant is responsible for: 1) participating in tracking of children who have been identified as having a hearing loss from diagnosis through early

intervention services, and 2) providing technical support, training, and consultation with families, audiologists, and other providers on the newborn hearing screening process, recommended practices in diagnosis of hearing loss and amplification fitting, and habilitation following diagnosis of hearing loss. Each of these audiology consultants will spend 25% of their time on activities related to this proposal.

Information Technology Services (ITS) provides computer programming and maintenance support for data systems throughout North Carolina. The FTEs assigned by ITS to a particular data system vary depending on the current needs of the project.

The funds requested in this application will be used for a surveillance quality monitor (1.0 FTE) and another surveillance specialist (1.0 FTE). Both of these positions will spend 100% of their time on activities related to this proposal.

The surveillance quality monitor will be responsible for tracking and surveillance for 10 North Carolina counties, coordination of quality assurance monitoring activities, including on-site chart reviews in birthing facilities and/or audiology practices, to insure unduplicated EHDI data, and assisting the Program Development and Evaluation Manager with preparation of data analysis reports to be used by EHDI Program staff to provide targeted consultation. This position will require graduation from a four-year college or university with a degree in psychology, sociology, social work, or a human service programmatic field; or graduation from a four-year college or university and two years of program evaluation or consultative experience in human service programs. Knowledge of data system use, quality assurance, and data reporting is preferred.

The surveillance specialist will be responsible for tracking and surveillance for the remaining 20 North Carolina counties, performing quality assurance monitoring to insure unduplicated

EHDI data, and assisting the Program Development and Evaluation Manager with analysis of data and preparation of data reports. This position will require completion of high school or equivalent and four years of progressively responsible clerical/administrative/office management experience; or completion of a two-year business administration program and two years of progressively responsible clerical/administrative/office management experience; or completion of a four-year program in a college or university with major emphasis on coursework in business administration, public administration, or other related field. Knowledge of data system use, quality assurance, and data reporting is preferred.

Evaluation Plan

Evaluation of the project will include a number of data sources. Much of the data on children will come from Hearing Link, including child-specific data for tracking infants through the screen-rescreen-diagnostic-amplification-intervention process. Comparison data will be obtained from Vital Statistics, Health Services Information System (HSIS), and other sources. The EHDI Program will incorporate the activities proposed in this application by linking the analysis of Hearing Link data with activities included in the previously described MCHB grant for Early Hearing Detection and Intervention Follow-up. Additionally, this plan will specify other qualitative and quantitative measures of performance of the North Carolina EHDI Program.

It is expected that because of this project's focus on enhancing accessibility of Hearing Link, the number of birthing facilities and service providers entering and reporting data will increase. This increase will likely be due to the greater ease of entering data, but will also be influenced by the technical assistance and consultation provided by the child health speech language and audiology consultants regarding North Carolina's administrative rules and legislative requirements, best practices in newborn hearing screening, and data analysis. The child health

speech language and audiology consultants will report monthly each occurrence of technical assistance and consultation by type and provider. This data will be used to capture the Program's increasing capacity as well as to shape the content of future consultation/training.

In addition to tracking the numbers of birthing facilities, public and private providers who begin using the web-based data entry and reporting system, the Program will compare provider-specific data submitted via the paper-based system used for newborn metabolic screening with data submitted using the web-based system. The purpose of these comparisons will be to ensure the accuracy of patient demographic data directly entered into Hearing Link or electronically transferred into the web-based system from other data sources, such as Laboratory Information Management Systems utilized by the State Laboratory of Public Health.

These same comparisons will be made as public and private providers begin using Hearing Link. The EHDI Program will compare provider-specific reporting trends via web-based data entry with those of the provider's reporting by paper in previous years.

Analysis of child-specific and agency/provider-specific data will also evaluate other trends including: (1) the timeliness of referrals for and completion of each stage of the EHDI process, (2) the correlation between reported percentages and national EHDI goals at each stage of the EHDI process, and (3) the identification of key variables affecting loss to follow-up rates. Data analysis will be utilized by the child health speech language and audiology consultants to provide targeted consultation to specific agencies and/or providers in order to correct any systemic or best practice issues that are detrimental to meeting Program goals and, thereby achieve successful outcomes for children and their families. Additionally, trend data will be used to implement more focused and intentional collaboration with other agencies responsible for children's special health needs through the activities proposed in this application. The EHDI

Program will also develop policies and procedures for sharing child-specific information across programs and agencies within North Carolina, as well as with programs in other states, to identify children with special health care needs. These policies and procedures will be developed in collaboration with other partners noted in this application.

Periodic summary data will be generated and analyzed to develop strategies to strengthen: (a) reporting by providers, (b) accuracy of data, (c) timeliness of data reporting, and (d) North Carolina's EHDI Program consultation and follow-up plans. Successful outcomes from these collaborative activities should result in better monitoring of care for children with special health care needs and fewer children lost to follow-up.