PROJECT ABSTRACT

Project Title: Early Hearing Detection and Intervention Tracking, Surveillance and Integration
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The purpose of this project is to enable Connecticut (CT) to enhance the tracking and surveillance system for the Early Hearing Detection and Intervention (EHDI) program to accurately identify, match and collect unduplicated individual identifiable data and accurately report the status of every occurrent birth throughout the EHDI process for the purpose of evaluating the progress of National EHDI goals and to develop and enhance the capacity of EHDI programs to integrate the EHDI system with other State screening, tracking and surveillance programs that identify children with special health needs.

CT implemented universal newborn hearing screening on July 1, 2000 and has a comprehensive EHDI infrastructure in place. The state averages 43,000 births per year, has thirty-one birthing facilities and has made tremendous strides in ensuring positive outcomes for infants with hearing loss and reducing loss to follow-up. Hospital and home birth data are reported to the DPH via the Newborn Screening System Child Health Profile (NSS CHP) web-based reporting system. The NSS CHP system integrates Newborn Bloodspot, Hearing Screening and Birth Defect Program data. The data is extracted daily and imported into each respective screening program's front end Microsoft Access database that is used for tracking, surveillance and programmatic activities. The NSS CHP has a link to the electronic vital records system (EVRS) and data are matched daily to verify that a CHP record has a corresponding birth certificate. There are 5 overt challenges addressed in this project: 1) The EHDI tracking application was written in Microsoft Access, which is not compliant with State Standards; 2) The link between the NSS CHP and EVRS only provides a one-way match which verifies an existing birth certificate to a known case in the NSS CHP and does not identify CT births that are missing from the NSS CHP; 3) The EHDI database does not presently have access to all of the data elements from EVRS that are necessary to conduct an analytical review of infants who may be lost to follow-up; 4) The EHDI data system does not have the capacity to collect standardized data on unduplicated individual infants and children from multiple reporting sources and identify those with late onset/progressive or progressive hearing loss; and 5) The CHP does not have the capacity to allow pediatric healthcare providers the ability to access and/or report through a web-based system.

This project will address moving the NSS CHP to a secure platform that is compliant with state standards, and will enhance the EHDI data system to accurately identify, match and collect unduplicated individual identifiable data and accurately report the status of every occurrent birth. The overall purpose of this project is to enumerate the Newborn Screening System from multiple sources and ensure that the tracking and surveillance data collected helps to minimize loss to follow-up and that the status and progress of every occurrent birth is monitored through all phases of the EHDI screening process.

PROJECT NARRATIVE

Background and Need: The purpose of this project is to enable Connecticut (CT) to improve the state mandated Early Hearing Detection and Intervention (EHDI) Program, which began on July 1, 2000, to enhance tracking and surveillance systems to accurately identify, match and collect unduplicated individual identifiable data; to enhance the Program's capacity to accurately report the status of every occurrent birth throughout the EHDI process for the purpose of evaluating the progress of the National 1-3-6 EHDI goals; and to develop and enhance the Program's capacity to integrate the EHDI system with other state screening, tracking and surveillance programs that identify children with special health needs. The CT Department of Public Health (DPH) is the lead agency that administers the EHDI Program and a comprehensive EHDI infrastructure is already in place in the state. CT's greatest resource is the legislation that has been in place since 1999, which mandates all birth hospitals to conduct universal hearing screening on newborns as "a standard of care". Informed consent for hearing screening is not required in CT, as it is mandated by state law. Parents do have the right to refuse screening based on a conflict with their religious tenets and beliefs. Since the EHDI program was implemented in CT in 2000, screening rates have consistently improved and in 2007, 99.2% of all newborns were screened.

CT developed the Newborn Screening System (NSS) using a web-based reporting system that allows hospitals to report real-time newborn biographical and demographic information, newborn bloodspot screening, hearing screening and birth defect data to the DPH in a secure, standardized manner. The process begins as the birth hospital creates an electronic record for each child born in the State. This unduplicated, identifiable data is sent to DPH via a secure, password protected virtual private network and is stored on a server platform that is maintained by the State Department of Information Technology (DoIT). DPH then conducts a daily extract of the new encrypted NSS data that is electronically transmitted to the Child Health Profile (CHP) including the related screening information for the Lab Screening, EHDI and Birth Defects Registry (BDR) Programs. This data is stored at DPH in an Oracle database serving as the back-end database for the three programs and has a direct link with the Electronic Vital Records System (EVRS). The NSS was designed with multiple validation rules in place that maintain the integrity of the data submitted to the DPH.

The NSS allows the hospital user access to the password-protected system beginning with the entry of the newborn’s medical record number. The system searches for the number and will not allow duplicate entries. Providing the medical record number does not already exist, the system will allow a new record to be created and will assign it an Accession Number. This Accession Number is an eight digit, unique identifier that is used by DPH for tracking and matching infant records in the EHDI, Newborn Laboratory Screening and Birth Defect Registry Programs. The newborn’s electronic record is comprised of four data panels (see Other Optional Attachments, CT NSS Data Panels.pdf). The first is the biographical panel, which is shared between all three programs. This panel collects detailed demographic and birth information for the mother and newborn, and the name of the child’s primary care provider (PCP) after discharge. Specific data elements are required fields and must be entered before the hospital can electronically submit the record to the DPH. The Laboratory panel collects newborn bloodspot specimen collection information and includes red blood cell transfusion data and other factors, which may affect the newborn’s result. The Hearing panel collects the hearing screening date, screening method, ear specific results, screener’s name, risk factors, audiological follow-up information and the method in which the parent and Primary Care Provider (PCP) were notified of the results. The fourth and final panel contains the diagnosis and referral information for the Birth Defect Registry. A unique feature of the NSS is that the hospitals have the ability to electronically transfer the child's electronic record to another hospital upon transfer of an infant. This enables the transfer hospital to access the newborn's record and enter the screening data when completed.

The NSS information specific to each of the three screening programs is currently viewable/available in the respective front-end Microsoft Access applications. The EHDI Program front-end application is an advanced system with the ability to generate tracking and surveillance reports with individual identifiable data, and statistical reports by hospital, that includes information such as the number of infants screened, 1st and 2nd screen results, number of missed screened, deceased, refused, referred, diagnosed and lost to follow-up (see Optional Other Attachments, CT Hearing Statistics for a Period Report.pdf). The child's diagnostic and early intervention information is manually entered into the EHDI database by program staff. The EHDI Program expanded its report capability in 2006 to identify the mother's race, age, and education level for those infants who failed the hearing screening and/or were diagnosed with a hearing loss. Through this project the DPH will expand the report capability to collect individual and identifiable demographic and biographic information on all newborns, based on the initial screening results.

In the recent year, it has become evident that the NSS hardware and software currently in place is nearly out-of-date, unsupported by a dedicated DPH Information Technology (IT) staff person knowledgeable in Oracle databases and vulnerable to system failure. Through this project, we propose to utilize a temporary IT Consultant with Oracle database experience to maintain the integrity of the EHDI program for the short-term and collaborate with current agency efforts to move older systems to a state-of-the-art Public Health Informatics Network (PHIN) platform.

The NSS including the EHDI and BDR Programs have been identified as high priority for movement to the PHIN platform. Due to limitations with the existing CT State Lab data management system the NBS Lab Screening Program, which is housed at the CT State Lab, will not have its database moved to MAVEN at this time. Beginning May 1, 2008, the CT State NBS Lab will begin replacing its current data system with a new Laboratory Information Management System (LIMS). Once the LIMS project is completed, the NBS Lab data system will reside on the MAVEN platform as a major component of the CHP.

According to 2007 U.S. Census Bureau estimates, CT's population is currently 3.5 million and consists of 79.9% Caucasian, 9.5% Black, 3.3% Asian and 5.2% Other. CT Vital Records statistics reported 42,067 occurrent live births in 2007, of which 41,741 (99.2%) were screened for hearing loss, 0.25% expired, less than 0.05% of parents refused the screening, and 0.5% had no hearing screen reported (over 50% of these are estimated to be out-of-hospital births).

Research has shown that 54% of newborns who passed the hearing screening at birth and were later found to have a hearing loss, had one or more risk factors. Although CT collects risk factor information from birth facilities and Diagnostic Testing Centers, there is a need to develop a more effective system to track and monitor children at risk for late/progressive hearing loss and assure ongoing audiological testing to promptly identify a hearing loss and connect the child to services. Infants who pass the hearing screen but have risk factors for hearing loss, or who do not pass the second screening, are referred to one of CT's 13 standardized Diagnostic Testing Centers for audiological follow-up and diagnosis. The Diagnostic Testing Centers submit audiological testing results to the DPH on a standardized reporting form (see Other Optional Attachments, CT Diagnostic Reporting Form.pdf). Information collected on the form includes the appointment or broken appointment date, method(s) of testing, type and degree of hearing loss specific to each ear, risk indicators, date of referral to early intervention and recommendations for follow-up. In 2006, 62 babies were diagnosed with congenital hearing loss and preliminary data for 2007 identified 47 diagnosed infants. The average age of diagnosis was 2.5 months in 2006, and 2.2 months in 2007, well below the national goal of three months. Audiologists play an important role not only in identifying infants with a hearing loss early, but also in assisting families to obtain prompt Early Intervention (EI) services for the child in an effort to maximize the child's speech/language development, and to avert delays. Infants are referred to Birth to Three, CT's EI program, at the time of diagnosis. The CT Department of Developmental Services (DDS) is the lead Agency for IDEA Part C and manages the Birth to Three Program. The DPH has a Memorandum of Understanding (MOU) with the DDS to share data between agencies on infants identified through the EHDI Program (see Other Optional Attachments, CT MOU, Birth to Three.pdf). Birth to Three has thirty-seven general programs and three specialty centers, American School for the Deaf, CREC/Soundbridge and the New England Center for Hearing Assessment and Management, that provide services for infants and children who are deaf or hearing impaired. Birth to Three staff developed *Service Guidelines for Families of Infants that are Deaf or Hearing Impaired* that is distributed to families upon referral and is available in English and Spanish. When EHDI staff receive a diagnostic report that identifies a baby with a hearing loss, EI is contacted to confirm the dates of referral, eligibility, and enrollment, eligibility status, date of amplification and the name of the center that the child is enrolled in. The EI information is then entered into the EHDI database. EHDI staff provides Birth to Three with the name of the Diagnostic Testing Center, the date of diagnosis and type and degree of hearing loss. More than 50% of the children diagnosed in 2006 had other medical conditions and were enrolled in a general EI program, rather than one of the three hearing specialty centers. EI staff contact the center for each child enrolled in a general program to be sure the hearing loss diagnosis is included on the child's individualized family service plan (IFSP). Until recently, only children with a bilateral hearing loss, greater than 40 dB in each ear, were eligible for EI services in CT. Children with a unilateral or mild loss were not eligible. On July 1, 2007, CT expanded the Birth to Three eligibility criteria to include all children with a permanent hearing loss of 25 db or greater in either ear, and/or persistent middle ear effusion that is documented for more than six months with a hearing loss of 30 db or greater. The CT average age of enrollment into EI in 2006 was 3.1 months, well below the national goal of 6 months. All infants enrolled in EI are linked to a medical home. All infants enrolled in EI have an IFSP written and signed by a multidisciplinary team of professionals, including the PCP. The DPH is home to Title V and manages the Children and Youth with Special Health Care Needs Program (CYSHCN). The EHDI program plans to utilize funds and services available through the CYSHCN program to assist with care coordination and follow-up, with a goal of reducing the numbers of infants who are lost to follow-up. The EHDI Program benefits from a working relationship with hospital screening staff, audiologists, and Birth to Three providers around the state in order to ensure that all newborns are screened, that infants who do not pass the screening receive appropriate audiological follow-up care and that infants diagnosed with a hearing loss are enrolled in EI. CT's goals are for all newborns to be screened for hearing loss at birth before hospital discharge, for diagnostic testing to be completed by 3 months, and if diagnosed, for the baby to be enrolled in Birth to Three for EI services by 6 months of age. It is therefore necessary to continuously address these topics on an individual basis, such as through site visits and chart reviews and statewide through annual educational conferences. All are crucial opportunities to bring the newborn hearing screening, diagnostic, and EI components together in order to enhance overall clinical and administrative procedures and maximize the benefit to families around the state.

There are 5 overt challenges addressed in this project: 1) The EHDI tracking application was written in Microsoft Access, which is not compliant with State Standards; 2) The link between the NSS CHP and EVRS only provides a one-way match which verifies an existing birth certificate to a known case in the NSS CHP and does not identify CT births that are missing from the NSS CHP; 3) The EHDI database does not presently have access to all of the data elements from EVRS that are necessary to conduct an analytical review of infants who may be lost to follow-up; 4) The EHDI data system does not have the capacity to collect standardized data on unduplicated individual infants and children from multiple reporting sources and identify those with late onset/progressive or progressive hearing loss; and 5) The CHP does not have the capacity to allow pediatric healthcare providers the ability to access and/or report through a web-based system. Each of these challenges is addressed in the following *Work Plan* section.

Work Plan: Goal 1: To improve the NSS applications by transitioning to a state-of-the-art application that resides on a platform that complies with State standards. Objective 1: By 8/1/08 the DPH will hire a temporary IT Consultant with Oracle database experience to maintain the integrity of the NSS back-end Oracle database and applications for the short-term needs of this project and to work with Consilience on the migration of the EHDI database to MAVEN. . There are several problems with the existing Microsoft Access application used by the EHDI Program: 1) The database is not compliant with State Enterprise-Wide Technical Architecture (EWTA) standards; 2) Microsoft Access is not secure, and it is difficult to make it secure; 3) It is not conducive to large data storage and requires periodic attention; 4) As the database grows in size the operating functions become slow and cumbersome; and 5) The connection between the

Oracle back-end and Access front-end has the potential to easily “break”. The EWTA standards were developed by DoIT to set technical and product standards as well as design principles, guidelines and best practices that will support the strategic direction of the State of Connecticut. The EWTA will be utilized by DoIT to build a statewide IT infrastructure that will support the individual needs of State organizations; the emerging need for multi-agency information sharing and applications; and the need to include outside providers, citizens and government entities as users of IT systems. Objective 2: By 12/1/08, the EHDI and BDR applications will be transitioned to a new state-of-the-art application (called MAVEN) through an existing contract with Consilience Software as is being done with other DPH programs like immunizations, disease surveillance, environmental public health, lead screening and occupational health. Much work has already been completed by Consilience staff for the above-mentioned programs as part of an agency-wide initiative to reduce data information silos; maximizing the use of shared hardware and software that will ultimately reduce related costs; use of the latest technologies; consistent IT database support; strict security procedures, firewall protection and recoverability features. In addition, the EHDI and BDR Programs are positioned for this transition, as the programs did a partial outline of the business needs of the program during the Discovery Phase in the summer of 2007, with Scientific Technologies Corporation (STC), Inc.. Any new data or application modifications that were not included in the STC Discovery Phase will be identified in a Gaps Analysis that will be completed by Consilience, paid for by another funding source (Environmental Public Health Tracking grant) and is included in the scope of work for the transition of the EHDI and BDR programs.

Goal 2: To improve the match between the EVRS and the CHP to allow identification of unduplicated, individual data on all occurrent births using multiple sources. Currently the DPH gets individual identifiable biographical and screening data on occurrent births from the birth hospitals through the NSS CHP web-based reporting system. An automated nightly match is performed between records received through the NSS CHP, to the corresponding birth certificate in EVRS. In 2007, there were a total of 92 NSS CHP records, which did not match to a birth certificate. In 2006, there were 42,179 occurrent births documented in EVRS, yet only 41,992 were reported through the NSS CHP, for a total of 187 missing records. There is currently no query mechanism in place to identify those occurrent births who had a birth certificate created, but were not reported through the NSS CHP. Without identifiable data on the records missing from the NSS CHP, EHDI staff are unable to ascertain whether the infants were screened. Many of the missing records are thought to be out of hospital births or infants who were born live and expired shortly after birth and were never entered into the NSS CHP. Gaining access to identifiable, unduplicated, individual data on all occurrent births will enable EHDI staff to collect and report standardized, aggregated information on screening results from all occurrent births. Objective 1: By 10/1/08, the IT Consultant will establish a query to identify those occurrent births that had a birth certificate created, but were not reported through the NSS CHP. The unmatched records will first be manually reviewed in an attempt to reconcile the match. Once it is determined that it is not a duplicate or existing record, a mechanism will be created to allow the EVRS record to be linked to the CHP record and will be available in the EHDI front-end databases. The NSS CHP uses an eight digit Accession umber as the unique identifier for each child and the system was designed not to allow duplicates. The 3rd and 4th digit of the Accession Number represents the hospital code of the birth facility. The IT Consultant will develop a mechanism for the CHP to automatically generate an Accession Number for the EVRS records not received through the NSS, using a designated code specific to this subgroup. In creating a two-way match between EVRS and the NSS CHP, EHDI and other screening staff will have access to the child's missing biographical, demographic and primary care provider (PCP) information and appropriate tracking and follow-up can be conducted to accurately report the screening status on all occurrent births. The accuracy of the match will be evaluated by randomly selecting 2% of the monthly births from each hospital reported through the NSS CHP and verifying congruency with the EVRS record.

Goal 3: To develop an analytical plan and conduct a multivariate analysis of loss to follow-up differences. Although the CT EHDI program currently tracks statewide loss to follow-up rates, it lacks the capacity to analyze individual cases by birthing facility, transfer facility, status of child upon discharge, racial ethnic subpopulations, number of other living children, maternal age, maternal education, insurance type, seasonal variations, or geographic location. It is important for EHDI Programs to analyze potential trends in infants who are lost to follow-up in the various stages of the screening process in an attempt to identify potential barriers in access to care, to develop plans for additional provider training and parent education, and to improve tracking and outreach strategies to reduce the numbers of infants who are lost to follow-up. <u>Objective</u> 1: By October 1, 2008, DPH will develop an analytical plan to assess differences in infants lost to follow-up. <u>Objective 2:</u> By December 1, 2008, the IT Consultant will modify the NSS CHP to collect the following fields from the EVRS: 1) number of previous children born alive and still living; 2) the education level of the mother; 3) the method of payment after the delivery; and 4) status of infant upon discharge (death data). This information is not currently available in the NSS CHP and will be used to evaluate differences in infants lost to follow-up as identified in the plan. This will provide EHDI staff with information pertaining to variables that may affect why a child is lost to follow-up, including identifiable information on infant deaths, which may explain why some infants were not screened or did not have follow-up. Access to the infant death data will improve the accuracy of reporting identifiable, unduplicated, individual data on all occurrent births and will eliminate the likelihood that a parent of a deceased child would be contacted regarding follow-up.

Objective 3: By May 1, 2009, the Consilience staff along with EHDI staff and epidemiologists will develop statistical reports for NBS staff to analyze infant lost to follow-up differences at various stages in the screening process based on screening results, birthing facility, transfer facility, race and ethnicity of the mother, number of other living children, maternal age, maternal education, insurance type, status of infant upon discharge, seasonal factors, and mother's geographic location in proximity to a Diagnostic Testing or Regional Treatment Center location. The data will be used to identify common variables that increase the loss to follow-up risk and will guide increased educational and outreach strategies.

Goal 4: To develop a mechanism to collect standardized data on unduplicated individual infants and children from multiple reporting sources and identify those with late onset/progressive or progressive hearing loss. Objective 1: By July 1, 2009, Consilience staff along with NSS staff, and DPH PHIN platform support staff will create a web-based reporting form for audiologists to report diagnostic and follow-up testing results to DPH. CT has fifteen Diagnostic Testing Centers that infants are referred to following a failed result on the hearing screen. The centers have standardized testing equipment and specialize in working with infants and children. In 2003, DPH created a standardized reporting form for audiologists to report individual and identifiable diagnostic information to the EHDI program (see Other Optional Attachments, CT Diagnostic Reporting Form.pdf). The form is completed by the audiologist at the time of the evaluation and is faxed or mailed to the DPH. The EHDI staff manually enters the diagnostic information, specific to that child in the EHDI database. In creating a web-based reporting form, the diagnosing audiologists will have access to the child’s initial and follow-up screening results and can add updated testing and diagnostic information as needed. DPH will pilot the web-based reporting form with two Diagnostic Audiology Centers (CT Children’s Medical Center and Lawrence and Memorial Hospital) over a six-month period, from 10/1/09 through 4/1/10. The centers will report diagnostic and follow-up testing data both electronically and on the existing paper reporting form. The EHDI staff will train the staff from the two Centers on how to access the web-based report through onsite, hands-on training. The EHDI staff will review 75% of the reports received for congruency and will make modifications to the form and/or conduct further education to the Centers as necessary. By April 1, 2010, the web-based reporting will be implemented in the remaining thirteen Diagnostic Audiology Centers. EHDI staff will conduct onsite training on how to access and use the form through hands-on training. Objective 2: By November 1, 2009, Consilience staff along with NSS staff and DPH PHIN platform support staff will develop statistical reports for the EHDI program to identify infants who passed their initial hearing screen and had one or more risk factors for hearing loss and are in need of follow-up testing. The CT EHDI Advisory Board recommends that those infants identified as at risk for hearing loss, receive an audiological assessment at least every six months up until age three, in addition to the ongoing surveillance of all children within the medical home based on the pediatric periodicity schedule. The EHDI Program currently collects risk factor data, as identified in the JCIH 2007 Position Statement, from the birth hospitals through the NSS CHP and from the Diagnostic Testing Center audiologists. The present data system however, lacks the capacity to generate the reports needed to identify those infants who passed the screening but have risk factors for hearing loss and are in need of ongoing audiological monitoring. These time-specific reports will identify at risk infants and will include a mail merge process that automatically generates follow-up reminder letters for the child's responsible party and PCP when prompted. EHDI staff will generate the reports and mail the letters on a monthly basis to serve as a reminder that the child is in need of audiological follow-up. The letters will be mailed out approximately six weeks before the appointment is needed to allow the family adequate time to schedule and secure an appointment. Objective 3: By November 1, 2009, Consilience staff along with NSS staff and DPH PHIN platform support staff will develop the statistical reports needed to analyze and report initial screening results, presence or absence of risk factors, and diagnosis of hearing loss including date of diagnosis, type and degree of hearing loss specific to each ear. This will facilitate collection of data and reporting of infants identified with a late-onset or progressive hearing loss.

Goal 5: To improve web-based access and reporting to the CHP from multiple sources.

Objective 1: By July 1, 2010, Consilience staff, EHDI staff and DPH PHIN Support staff will create a secure web-based access for pediatric healthcare providers allowing them access to the CHP records of children in their practice. There will be strict confidentiality requirements in place that limits the access of confirmation testing results to the NBS Lab Tracking and or EHDI Program staff only. The DPH will comply with all state and federal HIPAA laws that protect the confidentiality of health data. Objective 2: DPH will pilot the implementation of pediatric healthcare provider access to the CHP with two pediatric practices per month. This will be implemented through onsite training and 100% of the providers will successfully demonstrate the knowledge, skills and ability needed to access a record. An evaluation tool will be used to assess the knowledge gained during the training. Objective 3: By March 31, 2011, Consilience staff, EHDI staff and DPH PHIN Support staff will develop a secure mechanism for the NBS Genetic

Treatment Center Specialists to access the CHP and report confirmation genetics testing results to the EHDI program via a web-based reporting form. CT has two Regional Genetic Treatment Centers located at Yale New Haven Hospital and the University of CT Health Center. Providing the Regional Genetic Treatment Centers with access to the CHP will facilitate the EHDI Program's ability to collect the results of genetics testing that is conducted on infants who are referred for evaluation following a diagnosis of permanent congenital hearing loss. Another benefit is that the Genetic Treatment Centers will have access to the child's initial screening results, audiological diagnostic testing results and any risk factors that may be present. NBS staff will evaluate the completeness of the data by reviewing 75% of the paper reports submitted to verify congruency with the web-based report.

Collaborative Efforts: CT has a well-established EHDI Advisory Board, which was instrumental in getting the necessary legislation passed to implement universal hearing screening in CT. The Advisory Board is a multidisciplinary group of professionals with representation from: DPH, Birth to Three, Diagnostic Audiology Centers, the Commission on Deaf and Hearing Impaired, American School for the Deaf, birth hospitals, CT Otolaryngology Association, families of deaf infants and children and other community-based people who have interactions with the deaf and hearing impaired population. The group established recommended standards for diagnostic testing of infants and participates in annual educational conferences that are held for hospitals and audiologists. The Advisory Board meets monthly, continues to work collaboratively with the DPH and remains an active force in the EHDI program.

In 2006, the DPH collaborated with the University of Connecticut (UConn), Division of Human Genetics and developed a free web-based training for licensed healthcare providers on Newborn Screening in CT. The training targets MDs, APRNs, PAs, Midwives, RNs and other professionals who work with the newborn population and receive screening results. The training consists of seven individual sessions and covers both genetic and metabolic screening as well as newborn hearing screening. It offers free continuing medical education units upon successful completion of one or all of the session. To date, over 196 licensed health care providers from across the United States have completed the training.

CT has fifteen designated infant hearing Diagnostic Testing Centers to which infants are referred following a failed result on the newborn hearing screen. CT has a standardized reporting form through which the audiologists report individualized, identifiable follow-up diagnostic data to the DPH on each child evaluated. The Diagnostic Centers attend or participate in the annual Hearing Symposiums that the EHDI program sponsors and free CEUs are offered.

The DPH has had a MOU in place with the Birth to Three System since 1999. This MOU allows the two agencies to collaborate on a process that provides early identification and habilitative treatment of infants with hearing impairments, while maintaining patient confidentiality. This MOU permits the exchange of data from EI to EHDI to assure that families of infants who are diagnosed with a hearing loss are offered the opportunity for their child to receive EI services. CT has had legislation in place to screen “high risk” infants for hearing loss since 1985 and Birth to Three is well established in providing EI services to this population. CT has legislation in place that mandates audiologists and other health care providers to refer any child that has the potential for a developmental delay to Birth to Three within two days of acquiring such knowledge.

The DPH provides Title V CYSHCN funding to the Child Health & Development Institute (CHDI) to educate pediatric practices in the community on medical home initiatives and care coordination. The EHDI Program collaborated with CHDI to assist in educating pediatric practices in the state on the importance of assuring follow-up after a failed hearing screen and the importance of ongoing monitoring of the child's hearing, speech and language according to the AAP Pediatric Periodicity Schedule. Practices that support underserved populations will be targeted through Lunch & Learn site visits. The EHDI program in collaboration with the EHDI Advisory Board designed a poster titled, "What You Need to Know About Providing Health Care for Infants & Young Children with Hearing Loss". The reverse side of the poster includes the CT Audiology Diagnostic Testing Center locations and contact information. The intent of the posters is to educate providers and families about the EHDI process and to increase awareness about risk factors for hearing loss. The CHDI laminated the poster and will distribute it to each practices visited. Pediatric practices serving under-served populations will be targeted first.

CT has a well-established, toll-free telephone referral line that serves as a single point of entry for families to access information and services. The referral line is managed by the United Way of CT, 2-1-1 Infoline and is used for PCPs and others to refer families to EI and other programs.

Program Capacity: The DPH is the lead agency for public health initiatives in the state. The Public Health Initiatives Branch (PHI) is one of eight branches within the DPH. The PHI Branch's mission is to improve and protect the health of Connecticut's residents through: 1) the promotion of primary and preventive health care at every stage of life and through the identification of risk factors that contribute to chronic and infectious diseases; 2) the collection of data to assess and improve individual and population health; 3) disease surveillance and linked intervention activities such as patient counseling, public education, provision of vaccines or medicines, organization of special clinics; and 4) planning and development of a flexible emergency-response capability to address emerging disease problems. The Branch consists of the following sections: Family Health, AIDS and Chronic Diseases, Health Education, Management and Surveillance and Infectious Diseases. The EHDI program, as described in the state's MCHB Block Grant application, is located in the PHI, Family Health Section (FHS) in the CYSHCN Unit (see Mandatory Other Attachments, CT Organizational Chart.pdf).

CT Vital Records reports there were 42,067 occurrent live births in Connecticut in 2007, of which 41,741 (99.2%) were screened for hearing loss at birth, 0.25% expired; less than 0.05% of parents refused the screening, and 0.5% of babies have no hearing screening on record (over 50% of these are estimated to be out-of-hospital births). Vital record statistics recorded 162 and 107 home births in 2006 and 2007 respectively. In 2006, CT received newborn screening data on 99.5% of all occurrent births through the NSS CHP and 99.2% of all newborns were screened. In January 2008, the state's one licensed home birth practice began reporting newborn screening data through the NSS CHP, which will further improve the ability to report identifiable individualized data on all occurrent births. All birth facilities utilize a two-step screening program. Infants receive the first hearing screen using either otoacoustic emissions (OAE) or auditory brainstem response (ABR) screening equipment. Infants that do not pass the first screening have the screen repeated before discharge using the ABR method. As of 1/1/07 CT required all NICU babies to have an ABR screening to identify infants that may have auditory neuropathies. The average rate of referral from hospital hearing screenings in CT in 2006 and 2007 respectively was 0.90% and 0.83% of babies screened. EHDI staff closely monitor hearing screening referral rates to identify any hospitals whose referral rates exceed 4% and conduct site visits to those hospitals to provide education, technical assistance and to assist with quality improvement. Hospitals are encouraged to complete the two-stage hearing screening at birth and to refer all infants who do not pass the inpatient screening to a one of fifteen pediatric Diagnostic Testing Centers for evaluation and testing. The two-step screening method was implemented as a way of reducing the number of infants who refer from the hearing screen, to decrease the potential of infants being lost between hospital referral and audiological follow-up and to decrease unnecessary parental anxiety. Connecticut has seen a gradual decline in lost to follow-up rates over the last three years, due in part to enhancements made to the EHDI data system that facilitates tracking of infants through all phases of the EHDI process and the hiring of a 1 FTE EHDI Health Program Associate (HPA), dedicated to tracking and follow-up. The EHDI Tracking System has extensive report capabilities that staff utilize for tracking, follow-up and evaluation of program activities through the three components of the EHDI process. The EHDI database is used to generate reports on all babies born, who did not have the screening prior to hospital discharge. The HPA faxes the lists of infants without hearing screens to the birth facilities every other month to ascertain whether the newborn was truly not screened, or whether the screening was done and the results not submitted to DPH. When the HPA identifies an infant who was not screened, a letter is sent to the primary care provider of-record asking him or her to refer the child for an outpatient screening. A list of the CT Diagnostic Audiology Centers accompanies the PCP letter. Additionally, monthly reports are generated on babies who did not pass the newborn hearing screening at birth and for whom there is no documented follow-up at 2 months of age. The HPA tracks these babies by first sending a letter to the child's responsible party explaining the importance of taking the baby for follow-up testing and asking that DPH be notified of the screening results if the baby was evaluated by an audiologist. Furthermore, if the birth hospital indicates which diagnostic audiology center the family was referred to at birth, the HPA corresponds with that center to determine if the child was seen, and to obtain the diagnostic results which are then entered into the EHDI database. If the parent/responsible party tracking letter is returned to DPH (address unknown) or no response is received, a letter is sent to the child's primary care provider of-record within three months of birth, asking the provider to discuss the importance of follow-up with the parent and to refer the child for an audiological evaluation. A follow-up phone call is made to the PCP's office within 1 month of sending the initial letter to confirm whether the child is still seen in that practice, to verify that the provider received the baby's hearing screening results from birth, and to work with the provider to ensure the family knows where they can take their baby for follow-up testing and why it is important. If the provider's office responds that the baby was never or is no longer a patient in their practice, a phone call is placed to the baby's mother to determine whether follow-up has taken place or needs to be scheduled. Also, EHDI staff utilize data from the CT Immunization Registry Tracking System (CIRTS) to search for infants who cannot be located due to name, address or PCP changes, which serves as a second point of contact for the family. If all tracking options are exhausted, the family cannot be located and the child's hearing status remains unknown, the case is considered closed and the child is recorded as "Lost" in the EHDI database. Through diligent tracking and follow-up, CT has seen a gradual decline in lost to follow-up rates over the last three years. In 2004, twenty-four percent (24%) of infants were lost to follow-up between screening and audiologic diagnosis, 20.8% in 2005, and 13.7% in 2006. Although lost to follow-up rates have declined over time, there is more work to be done in the state to enhance the EHDI data system to identify key variables of infants who are lost to follow-up and to better identify children with congenital hearing loss and progressive/late-onset hearing loss as early as possible in order to maximize developmental outcomes and ensure school readiness. Hospital hearing screening results and interpretation of those results need to be clearly communicated to both parents and primary care providers (PCPs) to facilitate compliance with screening and diagnostic follow-up.

The CT EHDI program CT has a published an array of educational and informational materials for both families and providers that support all aspects of the EHDI Program. A brochure for families titled, “Listen Up!” explains the hearing screen and is given to families by the birth facilities prior to the screening. A second brochure titled, “A Parents Guide to Diagnostic Hearing Testing of Infants” was developed for families of babies who fail the newborn hearing screen. It explains the purpose and importance of taking the child for follow-up testing and lists the CT Diagnostic Testing Center locations. A third brochure titled, “What Parents Should Know About Genetics Testing and Evaluation of Babies with Hearing Loss” was developed for families of infants who are diagnosed with a hearing loss and referred for genetics testing and evaluation. The brochure explains the possible causes of the hearing loss, explains how the test is conducted as well as what information genetics testing can provide the family regarding the hearing loss. All brochures were developed in both English and Spanish and are available in hard copy as well as on the EHDI website.

The CT EI program published a service guideline for families of infants who are deaf or hard of hearing. The document explains the EI eligibility process, describes the various communication opportunities available to families, educates parents on how to advocate for their child, describes the roles of the audiologists and otolaryngologists, and lists resources available to families. The document was published in both English and Spanish and is available in hard copy and on the web. The service guideline is given to all families at the time of referral to EI.

EHDI program staff have attended the National EHDI Conferences annually since universal hearing screening was implemented in CT in 2000, and have presented abstracts to share information and collaborate with other experts in the field of hearing loss.

Staffing and Management Plan: Lisa Davis, RN, BSN, MBA, proposed Principal Investigator, serves as the State Maternal and Child Health Title V Director and Section Chief of the Family Health Section of the Connecticut Department of Public Health.

Donna Maselli, RN, MPH came to FHS in 1999 to develop and implement CT's Universal Newborn Hearing Screening program. Ms. Maselli established a strong partnership between DPH and the birth hospitals, pediatricians, audiologists, the Birth to Three System and developed comprehensive Hearing Screening Guidelines that were distributed to birth hospitals. Ms. Maselli worked with the CT Department of Information Technology (DoIT) to design, develop and test the Newborn Screening System and was the lead person assigned to work with DPH on the design, development and testing of the EHDI front-end data management system. Ms. Maselli is responsible for the overall EHDI program functions, including policy and database development, education and outreach, family education, cultural competency and ongoing program evaluation and quality improvement.

Amy Mirizzi, MPH, Health Program Associate was hired by DPH in 2005 to conduct EHDI tracking and surveillance, specifically to reduce the loss to follow-up rates. Ms. Mirizzi has been instrumental in assisting with modifications, maintenance and management to the EHDI Access database, education and outreach, program development, grants and contract management, and data analysis and interpretation. She assists in gathering, compiling, analyzing, evaluating and interpreting complex program statistics in order to monitor program progress and provide data for federal reporting.

Marcie Cavacas, MS, is the Supervising Epidemiologist in the Family Health Section. Ms. Cavacas is the State Systems Development Initiative Project Director, a member of the DPH PHIN Workgroup and a co-chair of the Virtual Health Bureau (VCHB) Data Committee. Each of these has a commitment to create a database designed to contain high-quality linked child health information that has the CHP as one of the central data sources.

DPH is currently in the process of filling an Epidemiologist 2 position. This Epidemiologist will be assigned to support the EHDI and BDR Programs in their data collection, analysis and reporting needs.

The temporary IT Consultant will maintain the integrity of the NSS back-end Oracle database and applications for the short-term needs of this project. Additionally, the temporary Consultant will work with the Consilience during the GAPS Analysis phase to outline of the remaining business needs of the program that were not addressed by STC in the Discovery Phase. The temporary Consultant will work with Consilience, PHIN support staff and DoIT and will represent the EHDI program on the migration of the NSS to the new state-of-the-art system (called MAVEN) that currently resides on the PHIN platform hosted at DoIT.

Evaluation Plan: This project will be evaluated through the various stages of the proposed project by staff from multiple disciplines. Since the existing EHDI data system is being moved to a new platform, it is crucial that the existing EHDI tracking system and report and query capabilities be functional and accurate once the platform is moved. This will ensure that the EHDI program tracking, follow-up and reporting functions will not be interrupted and that the platform move will be seamless. The EHDI staff will evaluate the performance of all existing tracking data and report functions once the database is moved to the PHIN platform. The overall program goals of 1-3-6 will be evaluated monthly to verify that CT is meeting the desired benchmarks at each phase of the EHDI process. The CT Work Plan Table (Mandatory Other Attachments, CT Work Plan Table.pdf,) outlines the detailed evaluation plan for the project.