## PROJECT ABSTRACT

Project Title: Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening
Funding Opportunity: #HRSA-08-067

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**Project Description:** 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 assure that all newborns are screened by one month of age and to reduce numbers of infants that are lost to follow-up after failure to pass the newborn hearing screen in an effort to improve quality developmental outcomes for infants identified with hearing loss (HL). A comprehensive EHDI infrastructure is already in place in Connecticut. The CT DPH will build on the established EHDI Program to ensure that all infants are screened before hospital discharge using standardized screening methods and that all home births receive a hearing screen using standardized screening methods; that timely audiological follow-up is provided for those infants for whom further assessment is indicated and that clear communication about the need for follow-up exists between pediatric health care providers and families; that all infants diagnosed with a hearing loss are enrolled in an EI program by six months of age and that all infants are linked to a medical home. This project addresses preventative and primary care services for infants and children with special health care needs.

There are five overt challenges addressed in this project: 1) there are infants who are born in hospitals and/or at home who do not have and/or pass a physiological newborn hearing screening examination and for whom there is no documented follow-up; 2) there is no standardized method of relaying hearing screen results and/or missed screens to pediatric healthcare providers upon hospital discharge; 3) there is no formal mechanism for assuring that those infants who screen positive and/or screen negative, but are at risk for late onset or progressive hearing loss, are linked to a medical home for ongoing monitoring and follow-up; 4) there is no formal mechanism to rescreen those newborns who are re-admitted to a hospital within one month of birth; 5) the current capacity of the DPH to offer culturally sensitive, linguistically competent education to families and resource information to health care providers needs to be enhanced.

**Project Goals:** This project will address the following goals: Goal 1: To expand the formalized EHDI program and tracking protocol to include screening of home births and to decrease the number of infants lost to follow-up overall; Goal 2: To standardize the language on hospital discharge summaries to provide interpretation of the hearing screening results in order to clarify that a referral on the newborn hearing screen indicates the need for audiological follow-up. Goal 3: To assure that all infants who do not pass the hearing screen and/or pass the hearing screen but have risk factors for late onset or progressive hearing loss receive ongoing monitoring and follow-up within a medical home to assure quality developmental outcomes. Goal 4: To implement a mechanism to re-screen all infants re-admitted to a hospital within one month of birth. Goal 5: To provide educational materials and opportunities for EHDI staff, families and pediatric health care providers on hearing screening, hearing loss, risk indicators, diagnostic testing and genetic evaluations, data reporting and early intervention options.

## PROGRAM NARRATIVE

### INTRODUCTION

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 assure that all newborns are screened by one month of age and to reduce numbers of infants that are lost to follow-up after failure to pass the newborn hearing screen and to assure quality developmental outcomes for infants identified with hearing loss (HL). Connecticut defines infants who are lost to follow-up as those who are not screened by one month of age and/or those who refer (or fail) their newborn hearing screening and do not have a complete diagnostic audiological evaluation documented. This definition excludes expired infants and those whose responsible party refused follow-up testing. 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 has a uniform state registry that incorporates standardized methodology, reporting and system evaluation. The Newborn Screening System Child Health Profile (NSS CHP) registry, integrates hospital newborn data for the Newborn Laboratory Screening program, the EHDI Program, and the Birth Defect Registry. Hospitals report to the NSS CHP through an internet-based reporting system, which allows the DPH to collect real time data through an import/export process. The system is password protected and data is sent via a secure, virtual private network. The process begins at the birth hospital where an electronic record is created for each child born. The hospital staff accesses the password-protected system and enters the infant's hospital medical record number. The system searches for that medical record and does not allow duplicate entries. When a new record is created an Accession Number is assigned by the system. The Accession Number is an eight digit unique identifier that is used for tracking infants in the EHDI Program, Newborn Screening Laboratory Program and the Birth Defect Registry. The newborn's electronic record is comprised of four data panels. The first is the biographical panel, which is shared between all three programs. The biographical panel collects the demographic and birth information for the mother and newborn. Specific data elements are required fields and must be entered before the hospital can electronically submit the record to the DPH. The second panel is the Laboratory, which collects newborn bloodspot specimen collection information, transfusion information and the status of the newborn. The third panel is the EHDI panel and it collects hearing screening results specific to each ear, date and method of screening, screener name, audiological follow-up referral location, parent and health care provider notification, and risk factors. The fourth panel contains the diagnosis and referral information for the Birth Defect Registry. Once the data entered by the hospital is complete for each individual panel, the record is electronically transmitted to a server at the DPH where the encrypted information specific to each program is available for extract by DPH program staff. A unique feature of the NSS CHP 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 record and enter the newborn's screening data when completed. The data are extracted from the NSS CHP and imported into the EHDI database daily. The EHDI data system has the ability to generate tracking and surveillance reports, as well as statistical reports by hospital, such as the number of infants screened, results of the first and second screens, and numbers not tested, deceased, refused, referred, diagnosed and lost to follow-up. Additional reports added in 2006 include demographic information including: race, age, and education level of the mother and low birth weight reports. The CT DPH will build on the established EHDI

Program to ensure that all infants are screened before hospital discharge using standardized screening methods and that all home births receive a hearing screen using standardized screening methods; that timely follow-up is provided for those infants for whom further assessment is indicated and that clear communication about the need for follow-up exists between pediatric health care providers and families; and finally that eligible infants are enrolled in an EI program by six months of age and that all infants are linked to a medical home. This project addresses preventative and primary care services for infants and children with special health care needs.

## NEEDS ASSESSMENT

According to 2007 U.S. Census Bureau estimates, Connecticut's population is currently 3.5 million and consists of 79.9% Caucasian, 9.5% Black, 3.3% Asian and 5.2% Other. While the total Connecticut population changed little since 1990, the ethnic diversity of the population continues to increase, with the largest percentage of minority populations residing in six CT cities: Bridgeport, Danbury, Hartford, New Haven, New London, and Waterbury. The 2000 U.S. Census data relects that 18.3% of CT's population speaks a language other than English, with Spanish being the predominant other language in 8.4% of the population. According to CT Vital Records statistics there were 42,067 live births in Connecticut in 2007, of which 41,741 (99.2%) were screened for hearing loss at birth, 0.25% expired prior to screening; 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). According to DPH vital record statistics, there were 162 and 107 home births in 2006 and 2007 respectively. There are 31 birthing facilities and one large midwife practice in the state. All hospitals 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 DPH collects screening data from birth hospitals through an internet-based reporting system. 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 pediatric audiologist for diagnostic 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. 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. CT does not consider a baby "lost to follow-up" until all means of contacting the family and the child's primary care provider have been exhausted. Although lost to follow-up rates have declined over time, there is more work to be done in the state to screen home births, to 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 among CT's children. Hospital 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. Presently the hospital discharge summaries include the ear-specific hearing screening results, listed as either Pass or Refer. Telephone calls by EHDI staff to PCPs during tracking have identified that the office staff often do not understand that a Refer result means that the child needs follow-up audiological testing. PCPs need further education on the interpretation of EHDI results, on the referral process and other available resources for families of children who are hard of hearing or deaf. Lastly, there is a need for the DPH to develop a better system to track children at risk for late/progressive hearing loss. Infants who do not pass the second screening are referred to one of the 13 designated Diagnostic Testing Centers for audiological follow-up and diagnosis. The standardized diagnostic audiology centers were identified through a survey in which they indicated to DPH that they were willing to see newborns and conduct the test battery recommended by the CT EHDI Advisory Board for the diagnostic hearing testing of infants who do not pass the hearing screening conducted at birth. The majority of these centers employ between one and three pediatric audiologists. There are three large, hospital-based centers that have more than three audiologists on staff able to provide diagnostic services to infants. The 13 Diagnostic Testing Centers submit audiological testing results to the DPH on a standardized reporting form (see Attachment 7, Other Documents). Information collected from the diagnosing audiologist includes date and method of testing, missed appointments, type and degree of hearing loss specific to each ear, risk indicators, and referral date to early intervention. Audiologists are an important resource in identifying infants with a hearing loss and assisting families in obtaining early intervention for their child in order to minimize speech, language, and developmental delays. In 2006, 62 babies were documented to have a diagnosis of congenital hearing loss and 2007 preliminary data identifies 47 babies diagnosed with hearing loss. The average age of diagnosis was 2.5 months in 2006, and 2.2 months in 2007. All infants identified with a hearing loss are referred at the time of diagnosis to the CT Birth to Three System, the state's early intervention (EI) provider. The DPH has a Memorandum of Understanding (MOU) with the Department of Developmental Services (DDS), lead Agency for IDEA Part C, to share data between programs on infants identified through EHDI. Birth to Three has three specialty centers that specialize in providing services for infants and children who are deaf or hearing impaired, American School for the Deaf, CREC/Soundbridge and the New England Center for Hearing Assessment and Management (NECHEAR). Birth to Three staff developed a *Service Guidelines for Families of Infants that are Deaf or Hearing Impaired* that is distributed to families upon referral. EHDI staff confirm enrollment (date of referral, date of eligibility, and center name) into the Birth to Three System for each individual case with DDS staff via telephone and the information is added to the EHDI tracking system. The EHDI staff provides Birth to Three staff with the date of diagnosis, type and degree of hearing loss. The Birth to Three specialty centers report the date of fitting for amplification on infants to DPH after parental consent is obtained. In 2006, 60 children were referred to CT Birth to Three and two children were not referred and were lost to follow-up between diagnosis and entry into early intervention. Forty-nine children were found eligible, but only 39 were enrolled. The average age of enrollment into EI in 2006 was 3.1 months of age. On July 1, 2007, CT Birth to Three eligibility criteria was expanded to include all children with a permanent hearing loss of 25 db or greater in either ear or persistent middle ear effusion that is documented for six months or more with a hearing loss of 30 db or greater. EHDI and Birth to Three worked together to notify families enroll children who had been diagnosed prior to the eligibility expansion and anticipate a higher enrollment percentage moving forward. All infants enrolled in EI are linked to a medical home. The DPH does not presently have a mechanism in place to identify the number of families linked to a family-to-family support network, however a PCP is identified by the birth hospital for each newborn that is reported through the NSS CHP. Additionally, the diagnostic audiology reports that are submitted to the DPH include the name of the referring physician. All infants enrolled in EI have an individualized family service plan (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). Although efforts to revise the CT CYSHCN have been underway in 2007, the EHDI staff were not directly involved the planning or development of the infrastructure. The EHDI program needs to utilize funds and services available through the CYSHCN program to assist in 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 newborns identified through universal hearing screening receive appropriate follow-up care and early intervention. The CT EHDI Program goals are for all newborns to be screened at birth before discharge or by one month of age, for diagnostic testing to be completed by three months, and if diagnosed, for the baby to be enrolled in Birth to Three for EI services by six months of age. It is therefore necessary to periodically address these topics on an individual basis, such as through site visits and small group meetings, and as a group through annual educational conferences. Both 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 five overt challenges addressed in this project: 1) infants who are born at home and/or in a hospital and do not have and/or pass a physiological newborn hearing screening examination are lost to follow-up; 2) there is no standardized method of relaying hearing screen results and/or missed screens to pediatric healthcare providers upon hospital discharge; 3) there is no formal mechanism for assuring that those infants who screen positive and/or screen negative, but are at risk for late onset or progressive hearing loss, are linked to a medical home for ongoing monitoring and follow-up; 4) there is no formal mechanism to rescreen those newborns who are re-admitted to a hospital within one month of birth; 5) the current capacity of the DPH to offer culturally sensitive, linguistically competent education to families and resource information to health care providers needs to be enhanced. Each of these challenges is addressed in the following *Methodology* section.

## METHODOLOGY

*Goal 1:* To expand the formalized EHDI program and tracking protocol to increase the percentage of newborns who complete screening by one month of age and increase the percentage of newborns who fail the initial screening and complete an audiological evaluation by 3 months of age. *Objective 1:* By December 1, 2008, DPH will partner with the one licensed midwife practice in the state to collect screening data on 100% of the home birth deliveries. The families of the home birth population in CT often do not seek conventional medical care and are reluctant to have their newborns screened. In February 2008, the EHDI Program used carryover grant monies and contracted with Birth and Beyond, the one licensed home birth practice in the state, to provide them with funding to acquire otoacoustic emission (OAE) screening equipment. The midwives will use the portable screening equipment to screen home births for hearing loss within 1 week of birth. It is hopeful that the families will allow the licensed nurse midwife, with whom they have established a trusting relationship, to conduct the noninvasive OAE screening on their infant.

Connecticut electronic vital records data identified 162 home births in 2006 and 107 provisional home births in 2007 as of 3/3/08. Babies born en route to a hospital or in a Primary Care Provider's (PCP) office are normally transported to a hospital, admitted and screened; however the planned home births generally remain at home and their screening status remains unknown. Through this project, the DPH will assist Birth & Beyond, the one licensed home birth practice in the state with approximately 150 births per year, to mirror the 31 existing birth facilities and report newborn hearing screening, newborn bloodspot screening, and birth defect registry data to DPH through the web-based Newborn Screening System. This will enable the EHDI program to collect real-time biographical and hearing and lab screening data on all occurrent births in Connecticut. The DPH will assign Birth & Beyond a unique code, which will identify the birth location as a residence in the DPH database. The newborn screening data will be transmitted to the DPH through a secure, virtual private network (VPN) and will be downloaded daily by DPH. *Objective 2:* The DPH will contract with a Systems Developer II to modify the EHDI database to include fields for Birth & Beyond in all tables and reports. This will enable the DPH to generate reports on the numbers of infants born at home who 1) had a hearing screen, 2) did not have a hearing screen, 3) refused, 4) did not pass and are in need of follow-up audiological testing and/or 5) verify that audiological follow-up was completed on those infants who failed the initial screening. The reports will identify individualized identifiable data that include the screening date, method, ear specific results, risk indicators, diagnostic status and enrollment into Early Intervention. *Objective 3:* By August 31, 2011, the overall lost to follow-up rate will decrease to 10%. One FTE Health Program Associate (HPA) will be utilized to track 100% of all in-state hospital and home births to assure that a hearing screen was conducted and that those who do not pass the initial screens receive timely audiological follow-up. The EHDI database will be used to generate reports on all babies born, who did not have the screening done by 1 month of age. The HPA will fax 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 will be 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 will accompany the PCP letter. Additionally, monthly reports will be 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 will track 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 indicated which diagnostic audiology center the family was referred to at birth, the HPA will correspond with that center to determine if the child was seen, and to obtain the diagnostic results which then will be 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 will be 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 will be 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 will be 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 and the family can not 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.

*Evaluation Goal 1:* Goal 1 will be evaluated using data in the EHDI database to measure the percentage of all newborn infants who complete screening by one month of age, using a benchmark of 99% and to measure the percentage of newborns who fail the screenings and receive audiological follow-up by 3 months of age, between 3 months and 6 months of age, and after 6 months of age.

*<u>Goal 2</u>:* To standardize the language on the 31 hospital discharge summaries to include an interpretation of the hearing screening results in order to clarify that a referral on the newborn hearing screen indicates the need for audiological follow-up. *Objective 1:* By September 1, 2009, all hospital discharge summaries will use standardized language to relay hearing screening results to the child's pediatric health care provider. Currently hospitals include the actual screening results on infant's discharge summary i.e. Pass/Pass or Refer/Refer. Telephone calls to PCPs by EHDI tracking staff have identified that although the hearing screen results were reported to the PCP, the office staff are unclear as to what a "Refer" result means. The EHDI staff will survey the thirty-one birth facilities to ascertain what information pertaining to the hearing screening result is provided on the discharge summary. The CT American Academy of Pediatrics (AAP) EHDI Chapter Champion will send letters to all chiefs of Pediatrics and/or Neonatology and advise them that along with the actual hearing screen result, the discharge summaries should include narrative language that explains that a failed result indicates the need for audiological follow-up. The letters will be followed up by site visits to each facility to confirm that the discharge summaries include clear follow-up instructions when indicated.

*Evaluation Goal 2:* Goal 2 will be evaluated by measuring the number of CT birth facilities that provide a narrative interpretation of the hearing screen result on the discharge summary, using a benchmark of 100%.

*<u>Goal 3</u>:* To assure that all infants who are not screened at birth and/or pass the hearing screen but have risk factors for late onset or progressive hearing loss, receive ongoing monitoring and follow-up within a medical home to assure quality developmental outcomes. *Objective 1:* By September 2011 the EHDI staff will conduct site visits to each birth facility and Diagnostic Testing Center to educate staff on the importance of reporting risk factors for hearing loss.

*Objective 2:* By September 1, 2009, the EHDI database will be enhanced to provide staff with the report capability needed to identify infants who passed the hearing screen but are at risk for progressive/late-onset hearing loss and are in need of audiological monitoring. Not all children develop a hearing loss at birth. Some hearing loss may have a delayed onset or be progressive in nature. The Joint Committee on Infant Hearing (JCIH) adopted a position statement in 2007 that identified risk indicators that require periodic monitoring of an infants hearing. It is important for health care providers to understand that a "pass" result from a hearing screening at birth does not guarantee that the child's hearing will always be normal. According to the JCIH, infants with one risk factor should receive a complete audiological evaluation by 24 to 30 months and those with more than one risk factor receive more frequent monitoring. In 2003, the DPH added fields in the Newborn Screening System to collect risk factors. Risk factors are also reported to DPH by the diagnosing audiologist on the Diagnostic Testing Reporting form. In 2007, the birth facilities reported 154 (0.4%) infants who failed the hearing screen and had one risk factor for hearing loss and 55 (0.1%) infants who failed the screen and had two or more risk factors. A total of 195 infants were reported as having passed the hearing screen and had one or more risk factors present. Although the risk factor data is collected from the birth hospitals, the EHDI staff does not have the necessary report capability to identify which infants with risk indicators passed the hearing screen at birth. The DPH will contract with a Systems Developer to make the necessary modifications to the EHDI Access and Oracle databases and tracking system. The EHDI staff will work with the developer on the design of the reports needed to provide identifiable data on those infants at risk and to modify the database to include fields and reports on follow-up testing, results and tracking status. *Objective 3:* By December 1, 2009, the EHDI program will partner with the Medical Home Initiative for Northwestern CT located in Waterbury, CT, to enlist their support in the tracking and follow-up of infants who require ongoing audiological follow-up. The EHDI staff will develop a system to provide the Medical Home Initiative for Northwestern CT with the infants in their region who are in need of ongoing audiological follow-up. The Medical Home Initiative for Northwestern CT will send letters to families of infants at risk, followed by telephone contact to remind them of the need for follow-up testing. *Objective 4:* DPH will establish a formal agreement with Birth to Three, our state's Part C EI provider, to obtain parental consent at the time of enrollment, which will enable EI to release the names of children enrolled who have a diagnosis of hearing loss. The DPH presently has a Memorandum of Understanding (MOU) in place with the CT Birth to Three System that requires EI to submit quarterly reports to the DPH of all infants enrolled with a diagnosis of a hearing loss. Despite this MOU, due to confidentiality issues, Birth to Three does not release the names to DPH and will only verify enrollment information on known diagnosed cases. Currently, children with a late onset/progressive hearing loss may be enrolled in Birth to Three without the EHDI staff's knowledge. There were 44 infants born in 2007 that were diagnosed with a hearing loss and of these 40 were referred to EI. Also, obtaining parental consent to release information to the DPH at the time of enrollment will enable the EHDI program to identify diagnostic and EI enrollment information on children who may be documented as lost to follow-up.

*Evaluation Goal 3:* Goal 3 will be evaluated by using data in the EHDI database to measure the number of infants with one or more risk factors for hearing loss that are referred for an audiological assessment at least once by 24 to 30 months of age, using a benchmark of 90%.

*Goal 4:* To implement a mechanism to re-screen all infants re-admitted to a hospital within one month of birth. *Objective 1:* By October 1, 2008, DPH will identify all CT hospitals that have a pediatric unit. The EHDI staff will contact each CT hospital to identify if they have a Pediatric Unit and will ascertain whether those hospitals have readily accessible hearing screening equipment available from a nursery, neonatal intensive care unit (NICU) or an Audiology Department within the hospital. The contact information for each Pediatric Unit will be obtained including the mailing address, Nurse Manager and Chief of Pediatrics name, telephone number, email address, and fax numbers. *Objective 2:* By December 1, 2009 all hospitals with pediatric units will develop a written policy for conducting hearing screens on infants re-admitted within one month of birth. The CT AAP EHDI Chapter Champion will send letters to all Chief's of Pediatrics advising them of the Joint Committee on Infant Hearing (JCIH) 2007 Position Statement recommendation that all infants re-admitted to a hospital within one month of birth be rescreened for hearing loss. The letters will advise each facility to develop a policy and procedure for conducting hearing screenings on newborns re-admitted within one month of age. The letters will be followed up by site visits by the EHDI Coordinator and AAP Chapter Champion to educate the pediatric staff on the importance of the hearing screen and to assist with policy development and the implementation of a hearing-screening program. *Objective 3:* By December 1, 2009, DPH will institute a reporting mechanism for pediatric units to provide DPH with the hearing re-screen results on infants re-admitted to a hospital within one month of birth. The DPH will match the children with the electronic birth record submitted through the Newborn Screening System and will add the re-screen information and update any known risk factors. The Systems Developer will modify the EHDI database to accept the re-screen date, method, location, and ear specific results. A report will be created to extrapolate the data from the system and generate individualized identifiable reports on re-screens within one month of age and the results.

*Evaluation Goal 4:* Goal 4 will be evaluated by measuring the number of hospitals with pediatric units that establish a policy and procedure to rescreen all babies re-admitted to within one month of birth, using a benchmark of 100%.

Goal 5: To provide educational materials and opportunities for EHDI staff, families and pediatric health care providers on hearing screening, hearing loss, risk indicators, diagnostic testing and genetic evaluations, data reporting and early intervention options. *Objective 1:* Two EHDI staff will attend the annual HRSA/CDC EHDI Conference to acquire knowledge about the latest advances in all aspects of EHDI. CT has allocated funding for two EHDI staff to attend the annual EHDI Conferences sponsored by HRSA and the CDC. The knowledge gained through participation in this conference will be used to enhance/expand the CT EHDI program and will be shared with other stakeholders within our state. *Objective 2:* The DPH EHDI program will conduct an annual conference(s) for audiologists, hospital screening staff, pediatric healthcare providers, midwives, early intervention providers and others to enhance their knowledge about hearing screening, risk factors, relaying results to parents, data reporting to DPH and plans and methods to reduce loss to follow-up. The full day event will feature speakers who are experts in their field and continuing medical education credits (CMEs) and continuing education units (CEUs) will be offered. A pre and post-test will be administered to evaluate knowledge gained and will be offered. *Objective 3:* DPH will disseminate informational brochures for families and healthcare providers on screening, diagnostics, risk indicators and genetic testing and evaluation. The DPH developed a brochure for families titled, “Listen Up!” which explains the hearing screen conducted at birth. The brochures are distributed to families by the birth facilities prior to conducting the hearing screen. A second brochure titled, “A Parent’s Guide to Diagnostic Hearing Testing of Infants” was developed and is given to families of newborns who do not pass the hearing screen at birth and are in need of audiological follow-up. Through this funding opportunity the DPH will reprint these brochures and distribute them to 100% of the CT birth facilities and the home birth practice. In 2006, the DPH contracted with the UConn, Division of Human Genetics to develop and implement a web-based provider training for pediatric health care providers on genetic testing in newborns. To date, 175 licensed healthcare providers from across the United States have successfully completed the training including Registered Nurses (RNs), Physician Assistants (PAs), Advanced Practice Registered Nurses (APRNs) and MDs. EHDI staff will continue to promote the web-based training during site visits, at health fairs and through the AAP and participation will increase by 5%. A brochure was also developed to educate families on genetics testing and hearing loss with the intent of explaining the risks and benefits of genetic testing for infants with hearing loss to help empower parents in the decisionmaking process for their child. The brochure was developed at an appropriate reading level (grade 4) and is available in English and Spanish. The brochures are distributed to families by licensed audiologists at the time of diagnosis and are downloadable from the DPH EHDI web site. *Objective 4:* By 8/31/2010, the DPH will distribute a parent survey to a random group of families to evaluate their satisfaction and understanding of the EHDI process. The DPH Epidemiologists will assist in identifying the survey sample size and sample selection and the EHDI staff will evaluate the survey results. The survey results will be used to improve or expand on the EHDI program and to revise the educational brochures if needed.

*Evaluation Goal 5:* Goal 5 will be evaluated by measuring the number of healthcare providers who participate in the “Newborn Screening in CT” web-based training, using a benchmark of a 5 % increase over 2007 and through an evaluation of the parent surveys in which 95% of the families will report an overall satisfaction with the screening, diagnostic and EI services provided.

**WORK PLAN**

| **Goal 1: To expand the formalized EHDI program and tracking protocol to increase the percentage of newborns who complete screening by one month of age and increase the percentage of newborns who fail the initial screening and complete an audiological evaluation by 3 months of age.** | | | | | | |
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| Steps/Activity | Indicators/ Measures | Outcome(s)/Output(s) | Responsible Party | Data Source | Start Date | Due Date |
| Objective 1.1 By December 1, 2008, DPH will partner with the one licensed midwife practice in the state to collect screening data on 100% of the home birth deliveries. | | | | | | |
| 1.1.1 Birth & Beyond will enter screening data in the NSS CHP. | Quantity of data in NSS CHP | DPH will have access to biographical and hearing and lab screening data on approximately 150 home births in CT. | Birth & Beyond staff | NSS CHP, EHDI database | 11/2008 | Ongoing |
| 1.1.2 DPH will collect screening data on 100% of home birth deliveries. | NSS CHP-Vital Records match | DPH will obtain hearing screening information on all occurrent births in CT. | EHDI staff | EHDI database, EVRS | 11/2008 | 12/2009 |
| Objective 1.2 The DPH will contract with a Systems Developer II to modify the EHDI database to include fields for home births in all tables and reports. | | | | | | |
| 1.2.1 Modify the EHDI database to include fields for home births in all tables and reports. | Executed contract | DPH will be capable of collecting real-time biographical, hearing, and lab screening data and audiological follow-up information on approximately 100% of home births in CT. | Systems Developer II & EHDI Coordinator | NSS CHP, EHDI database | 9/2008 | 9/2009 |
| Objective 1.3 By August 31, 2011, the overall lost to follow-up rate will decrease to 10%. | | | | | | |
| 1.3.1 Track 100% of all in-state hospital and home births to assure that a hearing screen was conducted by 1 month of age. | > 99% of newborns in CT will have a hearing screening conducted by 1 | Infants at risk for hearing loss and subsequent developmental delays are identified at birth. | EHDI HPA | CT birth facilities, EHDI database | 9/2008 | Ongoing |

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| | month of age | | | | | |
| 1.3.2 Track 100% of all in-state hospital and home births to assure that those who do not pass the initial screens receive audiological follow-up by 3 months of age. | 90% of infants who fail the newborn hearing screen will receive audiological follow-up | Infants at risk for hearing loss and subsequent developmental delays receive audiological evaluation by 3 months and EI services by 6 months of age, when indicated. | EHDI HPA | Diagnostic audiology reporting forms, EHDI database | 9/2008 | Ongoing |

| **Goal 2: To standardize the language on the 31 hospital discharge summaries to include an interpretation of the hearing screening results in order to clarify that a referral on the newborn hearing screen indicates the need for audiological follow-up.** | | | | | | |
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| Steps/Activity | Indicators/ Measures | Outcome(s)/Output(s) | Responsible Party | Data Source | Start Date | Due Date |
| Objective 2.1 By September 1, 2009, all hospital discharge summaries will use standardized language to relay hearing screening results to the child's pediatric health care provider. | | | | | | |
| 2.1.1 Survey the 31 birth facilities | 100% response rate | To ascertain what information pertaining to the hearing screening result is provided on the discharge summary | EHDI staff | Compilation of paper survey responses | 9/2008 | 12/2008 |
| 2.1.2 Send letters to all Chiefs of Pediatrics and/or Neonatology | Letters sent to 100% of Chiefs in CT | To adopt narrative language in each discharge summary that explains that a failed result on the hearing screening at birth indicates the need for audiological follow-up. | CT AAP EHDI Chapter Champion | Copies of each letter sent | 1/2009 | 2/2009 |
| 2.1.3 Site visits to each facility | 100% of facilities | To confirm that each hospital has a mechanism in place to include | CT AAP EHDI | Site visit summary | 2/2009 | 12/2009 |

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| | visited | language on the discharge summary that explains that a failure on the hearing screen indicates the need for audiological follow-up by 3 months of age. | Chapter Champion & EHDI Coordinator | reports documented | | |

| **Goal 3: To assure that all infants who are not screened at birth and/or pass the hearing screen but have risk factors for late onset or progressive hearing loss, receive ongoing monitoring and follow-up within a medical home to assure quality developmental outcomes.** | | | | | | |
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| Steps/Activity | Indicators/ Measures | Outcome(s)/Output(s) | Responsible Party | Data Source | Start Date | Due Date |
| Objective 3.1 By September 2011 the EHDI staff will conduct site visits to each birth facility and Diagnostic Testing Center to educate staff on the importance of reporting risk factors for hearing loss. | | | | | | |
| Objective 3.1.1 Conduct site visits to each birth facility and Diagnostic Testing Centers | Risk factor reporting will increase by 10% | To increase reporting of risk factors | EHDI staff | EHDI database, Chart reviews | 9/2008 | 12/2009 |
| Objective 3.2 By September 1, 2009, the EHDI database will be enhanced to provide staff with the report capability needed to identify infants who passed the hearing screen but are at risk for progressive/late-onset hearing loss and are in need of audiological monitoring. | | | | | | |
| 3.2.1 Contract with a Systems Developer to make necessary modifications to the EHDI Access database and NSS CHP | Executed contract | DPH will be able to generate reports that include identifiable individualized risk factor data as well as follow-up testing, diagnostic results, and tracking status data | Systems Developer & EHDI Coordinator | NSS CHP, EHDI database | 9/2008 | 9/1/2009 |
| Objective 3.3 By December 1, 2009, the EHDI program will partner with the Medical Home Initiative for Northwestern CT located in Waterbury, CT, to enlist their support in the tracking and follow-up of infants who require ongoing audiological follow-up. | | | | | | |
| 3.3.1 Hold planning meeting with the Medical Home Initiative (MHI) for Northwestern CT in | Written plan | Mechanism to assist in the tracking and follow-up of infants in the Waterbury area who require ongoing audiological follow-up. | EHDI staff | EHDI database | 5/2009 | 5/2009 |

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| Waterbury, CT | | | | | | |
| 3.3.2 Implement tracking system to send letters to families of infants at risk, followed by telephone contact to remind them of the need for follow-up testing. | Letters sent on a monthly basis | Primary care provider will ensure ongoing monitoring of child’s hearing status. | MHI for NW CT staff | EHDI database | 9/1/2009 | Ongoing |
| Objective 3.4 DPH will partner with Birth to Three, our state’s Part C EI provider, to obtain parental consent at the time of enrollment, which will enable EI to release the names of children enrolled who have a diagnosis of hearing loss. | | | | | | |
| 3.4.1 Add clause to existing Birth to Three parental consent forms stating that referral information will be released to DPH. | Signed parental consent | Allow data sharing between agencies within privacy regulations. | Birth to Three service providers | Birth to Three data system | 9/2008 | 12/2008 |
| 3.4.2 Birth to Three service providers will provide quarterly reports to DPH on all infants enrolled with hearing loss. | Quarterly reports | Mechanism to identify diagnostic and EI enrollment information on children who may be documented as lost to follow-up by EHDI as well as to identify children with a late onset/progressive hearing loss who may be enrolled in Birth to Three without EHDI documentation. | Birth to Three service providers | Birth to Three data system | 9/2008 | Ongoing |

| **Goal 4: To implement a mechanism to re-screen all infants re-admitted to a hospital within one month of birth.** | | | | | | |
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| Steps/Activity | Indicators/ Measures | Outcome(s)/Output(s) | Responsible Party | Data Source | Start Date | Due Date |
| Objective 4.1 By October 1, 2008, DPH will identify all CT hospitals that have a Pediatric Unit. | | | | | | |
| 4.1.1 Contact each CT hospital to identify if they have a Pediatric Unit and ascertain whether those hospitals have readily | 100% of CT hospitals will be contacted | Determine number of Pediatric Units in CT and current capacity in order to outline scope of outreach efforts. | EHDI staff | DPH licensing data, Nursery Nurse | 9/2008 | 10/1/2008 |

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| accessible hearing screening equipment available. | | | | Managers | | |
| Objective 4.2 By December 1, 2009 all hospitals with pediatric units will have a written policy for conducting hearing screens on infants re-admitted within one month of birth. | | | | | | |
| 4.2.1 Send letters to all Chief's of Pediatrics | Letters sent to 100% of Chiefs in CT | To advise them of the Joint Committee on Infant Hearing 2007 Position Statement recommendation that all infants re-admitted to a hospital within one month of birth be re-screened for hearing loss and advising each facility to develop a policy and procedure for conducting hearing screenings on newborns re-admitted within one month of age. | CT AAP EHDI Chapter Champion | Copies of each letter sent | 1/2009 | 3/2009 |
| 4.2.2 Follow up site visits | 100% of facilities visited | To educate the pediatric staff on the importance of the hearing screen and to assist with policy development and the implementation of a hearing screening program. | CT AAP EHDI Chapter Champion & EHDI Coordinator | Site visit summary reports documented and final written policy examples filed | 4/2009 | 12/1/2009 |
| Objective 4.3 By December 1, 2009, DPH will institute a reporting mechanism for pediatric units to provide DPH with the hearing screen results on infants re-admitted to a hospital within one month of birth. | | | | | | |
| 4.3.1 Modify EHDI database to accept the re-screen results. | Statement of work executed | DPH will be capable of tracking re-screen results on infants re-admitted to the hospital within 1 month of age. | System Developer & EHDI staff | EHDI database | 9/2008 | 12/1/2009 |
| 4.3.2 Plan for reporting re-screen results to DPH will be outlined in collaboration with Pediatric Units. | 100% facilities visited | Pediatric Units will have a plan in place to report hearing screen results on all newborns re-admitted within 1 month of birth. | EHDI staff & Pediatric Units | Written plans documented and filed | 4/2009 | 12/1/2009 |

| **Goal 5: To provide educational materials and opportunities for EHDI staff, families and pediatric health care providers on hearing screening, hearing loss, risk indicators, diagnostic testing and genetic evaluations, data reporting and early intervention options.** | | | | | | |
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| Steps/Activity | Indicators/ Measures | Outcome(s)/Output(s) | Responsible Party | Data Source | Start Date | Due Date |
| Objective 5.1 Two EHDI staff will attend the annual HRSA/CDC EHDI Conference to acquire knowledge about the latest advances in all aspects of EHDI. | | | | | | |
| 5.1.1 Attend National EHDI conference | Registration | Continuing education - to enhance/expand the CT EHDI Program and share with other stakeholders within CT. | 2 EHDI staff | Participant listing | 3/2009 | 3/2009 (annually) |
| Objective 5.2 The DPH EHDI program will conduct annual conferences for audiologists, hospital screening staff, pediatric healthcare providers, midwives, early intervention providers and others to enhance their knowledge about hearing screening, risk factors, relaying results to parents, data reporting to DPH and methods to reduce loss to follow-up. | | | | | | |
| 5.2.1 Annual educational/training conferences will be held | Participation from all CT birth facilities and all diagnostic audiology centers | Increase awareness of EHDI process - to identify program gaps that may be occurring and to discuss how those gaps might best be addressed | EHDI staff | Agendas and conference packets | 9/2008 | Annually |
| 5.2.2 A pre and post-test will be administered to evaluate knowledge gained. | Incorrect/ correct answer ratios; Likert scales | To assess knowledge gained and identify topics for future trainings | EHDI staff | Compilation of paper evaluation responses | 9/2008 | Annually |
| Objective 5.3 DPH will disseminate informational brochures for families and healthcare providers. | | | | | | |

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| 5.3.1 DPH will reprint and distribute educational brochures to CT birth facilities and Diagnostic Testing Centers. | Distribute to 100% of CT birth facilities | Brochures will be distributed as needed to birth facilities and Diagnostic Testing Centers. | EHDI staff | Excel spreadsheet record | 9/2008 | Ongoing |
| 5.3.2 DPH will continue to promote the web-based provider training: *Newborn Screening in Connecticut*. | Participation will increase by 5% | Educate child health care providers on the Newborn Screening Programs in CT | EHDI staff | Online participant registration records | 9/2008 | Ongoing |
| Objective 5.4 By 8/31/2010, the DPH will distribute a parent survey to a random group of families to evaluate their satisfaction and understanding of the EHDI process. | | | | | | |
| 5.4.1 Identify the survey sample size and sample selection criteria. | Representation of population being looked at | DPH will receive adequate response rates from families that are equally representative of all hospitals | DPH Epidemiologists | EHDI database | 9/1/2008 | 8/31/2010 |
| 5.4.2 Distribute surveys via mail with postage paid return envelope enclosed and due date stated | >35% response rate | Send to mothers of babies born within the previous 6 months | EHDI staff | EHDI database | 9/1/2008 | 8/31/2010 |
| 5.4.3 Evaluate survey results | > 35% response rate | Use to improve or expand on the EHDI Program and to revise the educational brochures if indicated | EHDI staff | SPSS | 9/1/2008 | 8/31/2010 |

## RESOLUTION OF CHALLENGES

*Goal 1:* To expand the formalized EHDI program and tracking protocol to include screening of home births and to decrease the number of infants lost to follow-up overall. The challenges anticipated in assuring that all infants are screened at birth and that those who fail the screening receive timely follow-up testing and those diagnosed with a hearing loss are enrolled in early intervention by six months of age are challenges that are ongoing. The first challenge of obtaining data on home births will be resolved by implementing a mechanism for Birth & Beyond to report on home births through the web-based Newborn Screening System. This will enable the DPH to verify that infants born at home receive the laboratory and hearing screenings at birth and that DPH receives a record of such births. Other challenges exist in locating those infants with name changes, a change in the PCP, and/or address changes after birth. This continues to be an ever-present obstacle in locating children in any screening program, however this will be resolved through diligent tracking. The EHDI program is fortunate to have a direct link with the electronic vital records system (EVRS), which provides EHDI staff with an alternate name for the baby and address as reported on the birth certificate. Since the link with EVRS was established two years ago, loss to follow-up rates have improved significantly in CT and are currently at 15%. The EHDI staff also has access to the child’s immunization record and can identify which PCP administered the last vaccine to the child. This is extremely helpful as the PCP can assist EHDI staff in locating the family/child.

*Goal 2:* To standardize the language on the 31 hospital discharge summaries to include an interpretation of the hearing screening results and to clarify that a referral on the newborn hearing screen, indicates the need for audiological follow-up.

The anticipated challenge on this goal may be individual hospital policy that prohibits changes to the discharge summary without going through appropriate administrative channels. It is expected that the active participation of our CT AAP Chapter Champion will facilitate the process to include an interpretation of the hearing screen result on each newborn’s discharge summary.

*Goal 3:* To assure that all infants who are not screened at birth and/or pass the hearing screen but have risk factors for late onset or progressive hearing loss, receive ongoing monitoring and follow-up within a medical home to assure quality developmental outcomes. The biggest challenge may be a lack of reporting of risk factors by the birth hospitals and/or Diagnostic Testing Centers. DPH will overcome this challenge through education conducted via site visits to the hospitals, primarily those with NICUs and to each of the Diagnostic Testing Centers. A second challenge may be that parents of children referred to EI refuse to consent to the referral information being released to the DPH. It is expected that the information provided to the parents at the time that the consent is being requested will be adequate to enable the parent’s to have adequate knowledge about the benefits of reporting to the DPH, and that parents will consent.

*Goal 4:* To implement a mechanism to re-screen all infants re-admitted to a hospital within one month of birth. The challenges anticipated in reaching this goal are delays in hospitals developing a policy and procedure to rescreen all babies re-admitted to a hospital within one month of birth. It is expected that with the support of the National and CT Chapters of the AAP, partnered with the recommendation for rescreening readmissions as outlined in the JCIH 2007 Position Statement, that hospital policy makers will see that this is a current standard and will adopt the policy for their institution. Site visits to the individual hospitals by our CT AAP

Chapter Champion and EHDI staff and support from the Chief of Pediatrics may assist in resolving this challenge.

*Goal 5:* To provide educational materials and opportunities for EHDI staff, families and pediatric health care providers on hearing screening, hearing loss, risk indicators, diagnostic testing and genetic evaluations, data reporting and early intervention options. There are no anticipated challenges associated with reaching this goal. Participation at the past annual EHDI conferences and annual Hearing Symposiums have included representatives from 100% of all birth facilities and 100% of all CT Diagnostic Testing Centers. It is expected that this will continue. Challenges in evaluating the EHDI program through parent surveys include lower than anticipated response rates due to name and/or address changes. This can be resolved by selecting infants born in the latter months of 2007, rather than by randomly selecting from all 2007 births. Over sampling can be conducted to eliminate the possibility of a less than desired response rate.

## EVALUATION AND TECHNICAL SUPPORT CAPACITY

Lisa Davis, RN, BSN, MBA, proposed Project Director, 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. She is a Registered Nurse and a Master of Business Administration as well as a current Robert Wood Johnson Executive Nurse Fellow. Ms. Davis has a great deal of experience managing federal grant programs and oversees all day-to-day operations and funding streams within the Section. She sits on the CT Developmental Disabilities Council and oversees the CT Early Childhood Partners (ECP) Grant (the state's MCHB Early Childhood Comprehensive Systems Grant (SECCS)). Her experience with the Department of Public Health also includes Supervising Nurse Consultant to the Women, Men, Aging and Child Health Unit, Maternal and Child Health Unit, and Children with Special Health Care Needs/Maternal and Child Health Unit. Ms. Davis also served as the Assistant Clinical Director of Community Health Services, Inc., in Hartford, CT, where she was responsible for the coordination of all clinical activities at the urban community health center and developed, implemented, and evaluated client satisfaction surveys.

Donna Maselli, RN, MPH, Nurse Consultant, was hired in 1999 to develop the Universal Newborn Hearing Screening program for CT. She serves as the EHDI Coordinator for the state and is a member and past chair of the, the CT EHDI Advisory Board, an Executive Board member of the Commission on Deaf and Hearing Impaired Advisory Board, a member and Past-President of the Directors of Speech and Hearing in State Agencies and a member of the Early Childhood Hearing Outreach Project. Ms. Maselli established a strong partnership between DPH and the birth hospitals, pediatricians, audiologists, the Department of Developmental Disabilities, Birth to Three System, the State Child Health Insurance Program (SCHIP) program and the CSHCN program. She developed comprehensive Hearing Screening Guidelines for the state that were distributed to birth hospitals in December 1999 and are currently being revised. Ms. Maselli is responsible for the overall program functions, including policy development, technical support to hospitals and diagnostic testing centers, consultation on database design and development, education and outreach, family education, cultural competency and ongoing program evaluation. Donna has 31 years of nursing experience in varied roles including direct care, administration, regulatory compliance and quality improvement. Ms. Maselli will continue to take the lead role in the maintenance of ongoing quality assurance mechanisms, education, database and reporting modifications and improvements, hospital technical assistance needs, and evaluation and data analysis activities associated with this project.

Amy Mirizzi, Health Program Associate was hired by DPH in 2005 to assist with EHDI tracking and surveillance and ultimately reduce the loss to follow-up rates. Her other responsibilities includes: Access database maintenance and management, consultation on database design, education and outreach, program development, grants and contract management, and data analysis and interpretation. She monitors the statewide program and develops and maintains quality assurance techniques in order to meet program goals and objectives and monitor hospital compliance with CT's universal newborn hearing screening statute. She provides technical assistance to CT's 31 birth facilities on issues related to newborn screening protocol and electronic reporting requirements and develops and implements needs assessment and evaluation methods for the EHDI Program, including site visits and programmatic surveys. Ms. Mirizzi assists in gathering, compiling, analyzing, evaluating and interpreting complex program statistics in order to monitor program progress and provide data for federal reporting. Ms. Mirizzi is the current Chair of the CT EHDI Advisory Board and serves on the Department of Education, "Together We Will" Planning Committee.

***[Since the grant was awarded there have been some staffing changes within the CT EHDI Program. The Nurse Consultant working in the EHDI Program is now Kathryn Britos-Swain, MSN, BS, RN. Amy Mirizzi now serves as the CT EHDI Coordinator.]***

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.

In 2006, the DPH contracted with the University of Connecticut (UConn), Division of Human Genetics and developed a free web-based training for licensed healthcare providers on the Newborn Screening in CT. The training targets MDs, APRNs, PAs, Midwives, RNs and other professionals who work with the newborn population and receives 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 CMEs and CEUs upon successful completion of one or all of the session. To date, over 200 licensed health care providers from across the United States have completed the training.

The Connecticut 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.

The DPH EHDI program has an integrated child health data system through which much of the data to be used in the evaluation for this project will be collected. Real-time infant newborn screening data has been collected through the NSS since 2002 and all 31 birth facilities electronically report to DPH. The NSS also has extensive report capabilities that staff utilize for tracking, follow-up and evaluation of program activities. The EHDI staff will evaluate the program at multiple points using the state developed data management system. The infant's age at screening will be reviewed to identify the percentage of newborns that receive a hearing screening by 1 month of age. The age at diagnosis will be reviewed to identify the percentage of newborns that fail the hearing screenings and receive audiological follow-up by 3 months of age. The data on those infants that are diagnosed with a hearing loss will be evaluated to assess whether the children are referred to EI by 6 months of age. Lost to follow-up rates will be tracked at the screening, diagnostic and EI points to identify at what point the children are lost. Infants who pass the newborn hearing screen and have risk indicators will be tracked to assure that the family and PCP are aware of the need for at least one complete audiological evaluation by 24 to 30 months of age and that it is conducted.

The evaluation of the individual goal described in this project will be conducted by the EHDI staff and are outlined under each specific goal in the narrative section.

## ORGANIZATIONAL INFORMATION

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 Public Health Initiatives Branch improves and protects the health of Connecticut's residents using a variety of methods: a) through 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; b) through the collection of data to assess and improve individual and population health; c) through disease surveillance and linked intervention activities such as patient counseling, public education, provision of vaccines or medicines, organization of special clinics; and d) through planning and development of a flexible emergency-response capability to address emerging disease problems such as West Nile virus and possible bioterrorism events such as anthrax or smallpox. The branch consists of the following sections: AIDS and Chronic Diseases, Family Health, 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) (see Attachment 6, Project Organizational Chart). Other programs in the FHS include Children with Special Health Care Needs, School and Adolescent Health (school-based health centers), Community Health Centers, Sickle Cell Disease Education, the Fetal Infant Mortality Review Program, Case Management for Pregnant Women, the Birth Defects Registry, and Early Childhood Partners. On a federal level, the Connecticut's Title V, CSHCN Program has been cited as a model for other states moving from the provision of direct care services to contracting with community-based agencies for these services.

Connecticut'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 were at 99.8% in 2007.

CT has a well-established EHDI Advisory Board, which was instrumental in getting the necessary legislation passed to implement universal screening in CT. The Advisory Board is a multidisciplinary group of professionals with representation from the following: DPH, Birth to

Three, audiologists, Commission on the Deaf and Hearing Impaired, American School for the Deaf, hospital nurse managers, a neonatologist, an otolaryngologist, other community based people who have interactions with the deaf and hearing impaired population, and families of deaf infants and children. The Advisory Board established recommended standards diagnostic testing of infants and the recommendations were incorporated into the EHDI Program Guidelines. The Advisory Board continues to meet on a monthly basis, continues to work collaboratively with the DPH and remains an active force in the EHDI program.

CT has thirteen designated infant hearing Diagnostic Audiology Centers to which infants are referred following a failed result on the newborn hearing screen. There is a mechanism in place for the centers to report individualized, identifiable follow-up diagnostic data to the DPH on each child seen.

The DPH EHDI program has an integrated child health data system that links Newborn Hearing, Laboratory Bloodspot Screening, Birth Defect Registry and matches each birth record to the Electronic Vital Records System. Data for project will be collected through the Java-based NSS CHP and exported daily to the Child Health Profile (CHP) dataset where it can be imported into the EHDI Access database. Real-time infant newborn screening data has been collected through the NSS CHP since 2002 and all 31 birth facilities electronically report to DPH. The NSS CHP also has extensive report capabilities that staff utilizes for tracking, follow-up and for state and federal reporting. The EHDI staff will evaluate the program at multiple points using the state developed data management system. The infant's age at screening, method of screening, age at diagnosis, and age of enrollment in EI will be evaluated to assess whether CT is meeting national recommendations. Lost to follow-up rates will be tracked at different points in the process including lost at screening, lost at diagnosis or lost at enrollment in EI. Infants who pass the newborn hearing screen and have risk indicators will be tracked to assure that the family and PCP are aware of the need for audiological follow-up and that it is conducted.

The DPH has had a Memorandum of Understanding (MOU) in place since 1999, with the Department of Developmental Services (DDS), the lead agency for IDEA Part C in Connecticut (see Attachment 5, Letters of Agreement). 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 DDS to DPH to assure infants with diagnosed hearing loss are enrolled in the Birth to Three System. CT's well-established early intervention program (Birth to Three) is experienced in working with infants with hearing loss since legislation has been in place for birth hospitals to screen infants at "high risk" for hearing loss since 1985. Birth to Three staff developed a *Service Guideline for Families of Infants that are Deaf or Hearing Impaired* and have three centers that specialize in working with hearing impaired infants and children. Birth to Three has endorsed this project as evidenced by a letter of support (see Attachment 5, Letters of Agreement).

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. CT has a well-established single point of entry telephone referral line that is managed by United Way of CT 2-1-1 Infoline.

The facilities and equipment available are adequate to sustain this project. The DPH EHDI Program is housed in a complex of multiple state agencies and is located on Capitol Avenue in downtown Hartford, CT. The Governor's Office and Legislative Office Building are two blocks east of DPH and are within walking distance.

The DPH maintains appropriate administrative and clerical services for staff. The agency's computer networking system is serviced and maintained by in-house IT staff with network server and other additional support provided by the state Department of Information Technology (DoIT). The agency has dedicated web, file, and database servers to support program initiatives as well as copying, word processing, image processing, desktop publishing, and data and statistical analysis capabilities within its offices. As in-kind, the DPH will provide office furniture, office space, conference rooms, vehicle access, clerical support, phone and Internet services, fax and copying access, office supplies and computer equipment for existing staff. In February 2008, the DPH/Family Health Section recently had to remove from use an older model laptop that was not compatible with State security encryption software; therefore, funds have been allocated in this proposal to purchase a laptop computer for out-of-office meetings, presentations and trainings.