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 reduce the number of infants who are lost to follow-up after failure to pass the newborn hearing screen in order to assure quality developmental outcomes for infants identified with hearing loss (HL). Connecticut defines infants who are lost to follow-up as those who refer (or fail) their newborn hearing screening and do not have a complete diagnostic audiological evaluation documented by 12 months of age. 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 a virtual private network (VPN), which allows the DPH to collect real time data through an import/export process. The process begins at the birth hospital where an electronic record is created for each child born. Specific data elements are required fields and must be entered before the hospital can electronically submit the record to the DPH. 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. 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.

The CT DPH will build on the established EHDI Program to ensure that clear communication about the need for follow-up exists between pediatric health care providers and families; that timely follow-up is provided for those infants for whom further assessment is indicated; 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

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 a repeat screening 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 neuropathy/dys-synchrony. 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 (rather than returning to the hospital for an outpatient

rescreen). The two-step screening method was implemented to reduce 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. All newborn hearing screening data is electronically reported by the birth hospital to the DPH.

According to CT Vital Records provisional data there were 40,930 live births in Connecticut in 2008, of which 40,672 (99.4%) have documented hearing screening results to-date, 0.27% died prior to screening; less than 0.04% of parents refused the screening, and 0.32% of babies (n=132) have no hearing screening on record. CT electronic vital records data identified 170 provisional home births in 2008, as of 5/28/09, which may account for the majority of missing hearing screening results. The average rate of referral from hospital hearing screenings in CT in 2007 and 2008 respectively was 0.82% and 1.14% of babies screened. EHDI staff closely monitor hearing screening referral rates to identify any hospitals whose referral rates exceed 4% (in accordance with JCIH Position Statement recommendations) and conduct site visits to those hospitals to provide education and technical assistance and to assist with quality improvement.

In February 2008, the EHDI Program used carryover grant monies and contracted with Birth & Beyond, the one licensed home birth practice in the state, to provide them with funding to acquire otoacoustic emission (OAE) screening equipment. The midwives use the portable screening equipment to screen home births for hearing loss within 1 week of birth. Through this project, the DPH has worked with Birth & Beyond to begin electronically reporting newborn screening data to DPH through the NSS CHP, which allows the EHDI program to collect real-time biographical and hearing data on this cohort of CT home births.

Infants who do not pass a second hearing screening prior to discharge from a CT birth facility are referred to one of the 11 designated diagnostic testing centers for audiological follow-up and diagnosis. Infant diagnostic audiology centers were identified through a survey of all CT audiologists (last conducted in 2005) 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. These centers submit audiological testing results to the DPH on a standardized paper reporting form via fax. 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. 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 69.4% were diagnosed within 3 months of age; another 17.7% were diagnosed between 3 and 6 months of age (average age at diagnosis: 2.5 months). CT 2007 data identifies 66 babies with congenital hearing loss but only 57.6% were diagnosed within 3 months of age; another 24.2% were diagnosed between 3 and 6 months of age (average age at diagnosis: 2.4 months).

All infants identified with a hearing loss are referred at the time of diagnosis to the CT Birth to Three System, the state's IDEA Part C early intervention (EI) provider. On July 1, 2007, CT Birth to Three expanded its eligibility criteria 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. Birth to Three has three hearing specialty centers that specialize in providing services for infants and children who are deaf or hard-of-hearing: 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.

The DPH has had a Memorandum of Agreement (MOA) in place since 1999, with the Department of Developmental Services (DDS), the lead agency for IDEA Part C in Connecticut (see Attachments, *B23 MOA*). This MOA allows the two agencies to collaborate on a process that provides early identification and habilitative treatment of infants with hearing impairments, without violating privacy regulations. This MOA permits the exchange of data from DDS, Birth to Three, to DPH to assure infants with diagnosed hearing loss are enrolled in the Birth to Three System. Early this year, the DPH EHDI Program revised the Memorandum of Agreement (MOA) with the DDS, Birth to Three Program in order to enhance the data-sharing piece of the agreement. Due to IDEA confidentiality regulations, Birth to Three does not release the names of enrolled children with hearing loss to DPH and will only verify enrollment information on known diagnosed cases. EHDI and Birth to Three staff developed a reporting form to accompany the existing Birth to Three parental Release of Information Form, which includes the child's name, date of birth, birth hospital, PCP, date of audiological evaluation, type and degree of hearing loss, hearing aid/cochlear implant candidacy criteria and fitting/implant dates, and risk factor information. 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 as well as to better identify children with late onset/progressive hearing loss.

In 2006, 60 children (96.8% of babies identified with congenital hearing loss) were referred to CT Birth to Three and two children were not referred and thus were lost to follow-up between diagnosis and entry into early intervention. Forty-nine children were found eligible, but only 39 were enrolled. In 2006, 74.4% of babies were enrolled in EI before 6 months of age (average age of enrollment: 3.1 months of age). In 2007, 61 children (92.4%) were referred to CT Birth to Three and five children were not referred and thus were lost to follow-up between diagnosis and entry into early intervention. Fifty-two children were found eligible, and 100% were enrolled in EI. In 2007, 76.9% of babies were enrolled in EI before 6 months of age (average age of enrollment: 3.9 months of age).

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. EHDI staff track these babies through letters to the child's responsible party and primary care provider on record, explaining the importance of taking the baby for follow-up testing and asking that DPH be notified of the results if the baby was evaluated by an audiologist. 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 will be placed to the baby's mother to determine whether follow-up has taken place or needs to be scheduled. EHDI staff also correspond with audiology centers around the state that have been identified as infant diagnostic testing locations to determine if the child was seen, and to obtain diagnostic results. 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.

Tracking is ongoing, and Connecticut has seen a gradual decline in lost to follow-up after failure to pass newborn hearing screening rates over the last 5 years – 2003: 30.3%, 2004: 24.2%, 2005: 21.1%, 2006: 16.4%, and 2007: 15.5%. Although lost to follow-up rates have declined over time, there is more work to be done in the state 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.

CT's cooperative agreement with the CDC outlines a plan to conduct an analysis of lost to follow-up rates and demographic differences. Due to large socio-economic gaps among CT's population, disparities in follow-up are projected across race/ethnicity, income, and educational lines. Nearly 89,000 children in Connecticut lived in poverty in 2006. Nearly one-quarter of the state's children live in low-income households with income at or below 200 percent of the federal poverty level. The children who make up the largest proportion of the achievement gap in our state are precisely those whose home environments have multiple, recurrent, and unrelenting challenges. Children who are poor often face extensive health problems and family stress factors. Adding to the challenges, more young children are poor or near poor, facing obstacles that impinge on their life choices before they ever open the kindergarten door. Growing numbers of young children in Connecticut are from different cultures. The fabric of diversity is strong but the disparities in income for children are also great. There are about 248,000 children under six years of age in Connecticut. Twenty-eight percent (69,440) live in low-income families (families earning less than twice the federal poverty level or less than $40,000 for a family of four). Disparities are growing in health and developmental outcomes. Connecticut data highlights severe inequities in early child development, health and learning for many African-American and Hispanic children and their parents. Barriers to young children's health care access include family mobility, lack of culturally competent providers, inconvenient office hours and locations, and language and "health literacy" (understanding medical language) problems. Care coordination is poor, as childcare and family support services are not well linked to health care services, prevention services are not well coordinated, and many children are lost to the system when no longer eligible for services.

There are four overt challenges addressed in this project: 1) there is a lack of public and provider awareness about newborn hearing screening and appropriate follow-up protocol; 2) there is a need for clearer communication about the need for timely follow-up between pediatric health care providers and families; 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; and 4) 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

The following goals are aimed at implementing strategies to encourage families and support professionals involved in EHDI in motivating families to (1) complete follow-up after their baby fails to pass the newborn hearing screening prior to discharge from the hospital and (2) to facilitate the follow-up process between hospital screening and audiologic diagnosis. (Note: As described previously, there is no formalized hospital outpatient rescreening process in place in CT.)

Goal 1: Implement innovative educational initiatives to supply health care providers with the knowledge and information necessary to support and encourage families to complete timely follow-up after their baby fails to pass the newborn hearing screening.

Objective 1.1: By 3/31/2010, educational initiatives targeting a reduction in loss to follow-up rates between hospital screening and audiologic diagnosis will be implemented at the hospital-level. CT's Universal Newborn Hearing Screening Program is approaching its 10-year anniversary. Despite biennial educational conferences, state developed program guidelines (with several revisions), periodic hospital site visits, and regular technical assistance communications with the 31 birth facilities in the state, there are concerns regarding whether consistent leadership exists at the forefront of hospital universal newborn hearing screening programs; as measured by percent screened at birth and percent of referrals with documented follow-up testing. All CT hospital's consistently screen 99% of newborns, but lost to follow-up rates among individual facilities ranged from 7.3% to 66.7% (mean = 28.8% LTF*)*, three hospitals reported no referrals, and nine hospitals had 100% follow-up in 2007.

A hospital Newborn Hearing Screening Program information gathering survey was developed and distributed in May 2009 (see Attachments, *NBHS Survey*). The purpose of the survey was multifaceted. First, the EHDI Program used this survey to ensure accurate Nurse Manager contact information for all 31 birth facilities and one midwife practice. Efforts to maintain a comprehensive list of contacts at each of the 31 CT birth facilities are ongoing; however, well baby nursery and NICU Nurse Manager turnover is high which presents a challenge to ensuring program continuity. The survey also included questions regarding hearing results notification procedures as well as how many hospitals schedule a follow-up appointment for a baby prior to discharge, when he/she does not pass the newborn hearing screening. Based on the information gained from the hospital surveys, a standardized hearing results written notification slip or label may be developed to attach to each newborn's discharge summary. This proposed project would piggyback on this idea. Scripts will be developed for and distributed to hospital staff in order to provide concrete language for delivering verbal newborn hearing screening results to parents in the hospital. Separate cue cards will be made available for various scenarios including: passing, passing with risk factors, not passing, not passing with risk factors and frequently asked questions. The Newborn Hearing Screening Training Curriculum: Competency-Based Training for New Hearing Screeners PowerPoint presentation (infanthearing.org) includes these scripts, which will be used as a template and then modified and adopted for CT birth facilities.

Furthermore, EHDI staff will work to maintain more regular contact with well baby nursery and NICU Nurse Managers via a quarterly (if not more frequent) EHDI tips email (*not yet named*) that will be designed to provide Nurse Managers with regular reminders regarding EHDI best practices. It will be distributed in the form of bullet points that can be shared at staff meetings to encourage better top-down communication and to emphasize and repeat key EHDI messages at the hospital-level. This will provide a forum for both highlighting success stories and raising concerns identified by EHDI staff through management of the program.

*Evaluatio*n: In order to assess the effectiveness of objective 1.1 in reducing loss to follow-up rates between hospital screening and audiologic diagnosis, individual hospital follow-up rates will be compared against themselves between 2009 and 2011. During this time each hospital will individually demonstrate improvements in loss to follow-up, as reflected by referral and diagnostic data documented in the EHDI database.

Educational initiatives targeting a reduction in loss to follow-up rates between hospital screening and audiologic diagnosis will be implemented at the pediatric primary health care provider-level. ***Objective 1.2:*** By 8/31/2010, the Child Health and Development Institute of CT (CHDI) will develop an EPIC (Educating Practices in the Community) Module on early hearing detection and intervention in order to lead to improved quality of care related to hearing loss and risk indicators for hearing loss among pediatric-age patients in the primary care setting. CHDI staff will develop and present the EHDI module in collaboration with pediatric experts and community service providers. The module will be presented to five child health practices in grant year 1, and up to 20 practices in each subsequent grant year..

EPIC is a program of the CHDI, with support from the state chapters of the American Academy of Pediatrics and American Academy of Family Physicians, thus making CHDI uniquely qualified to conduct these activities. EPIC provides practice-based education to pediatric and family medicine providers on a wide range of issues and topics. EPIC presentations are delivered to the entire practice team, including nurses, physicians, and office staff. EPIC is based on the academic detailing model that pharmaceutical companies use to educate physicians about new products. A physician or other health care professional with expertise in the topic area visits the practice at a convenient time, brings food, delivers a short presentation, answers questions, and leaves resources to help the practice implement change. The EPIC program works to better enable practices to function more effectively as medical homes, strengthen developmental and behavioral services, enhance early and ongoing detection of developmental and behavioral problems, and prevention and intervention strategies. EPIC has demonstrated success in changing practice behavior and increasing the effectiveness of early detection efforts. An evaluation of the module on surveillance and screening showed a significant increase in the identification of children with developmental and behavioral concerns and an increase in referrals to Child Development Infoline (CT's single-point-of-entry for referral to early intervention services). Studies have shown that primary care providers are more likely to play a role in follow-up if they are well informed about paths of follow-up and services for their patients (see Attachments – Letters of Agreement).

Key messages to be included in the EHDI EPIC module are: information about the newborn hearing screening; follow-up paths for babies who do not pass the screening and for babies who

pass the screening but have risk indicators for hearing loss; information regarding late onset / progressive hearing loss and what the risk indicators have been identified for hearing loss in childhood, with an emphasis on parental concern (i.e. "If there are ever any concerns about a child's hearing, speech, and/or language development, REFER the child for an audiological evaluation as soon as possible."); as well as information on Child Development Infoline and Birth to Three.

*Evaluatio*n: It would be difficult to ascertain the isolated effect of the EPIC module in reducing loss to follow-up rates; however, CHDI can measure the commitment of the pediatric practices they visit to ongoing monitoring of children's hearing in the medical home based on self-report. Overall, this project aims for 90% of infants who fail the newborn hearing screening to receive audiological follow-up.

Goal 2: Build on the established Children and Youth with Special Health Care Needs (CYSHCN) system and infrastructure in Connecticut to facilitate timely and appropriate follow-up for infants who do not pass newborn hearing screening. The DPH is home to Title V and manages the CYSHCN Program. The EHDI Program will leverage services available through the existing CT Medical Home Initiative (MHI) for CYSHCN community-based system of care to assist in care coordination and follow-up with a goal of increasing the percentage of infants who receive follow-up by three months of age and reducing the numbers of infants who are lost to follow-up.

Objective 2.1: By 4/30/2010, the five Connecticut MHI for CYSHCN care coordination contractors will be equipped with tools to integrate early hearing detection and intervention best practices into their community-based system of care. Services for Children with Special Health Care Needs (CSHCN), supported by the Title V Maternal and Child Health Block Grant, were reorganized by the DPH in 2005. DPH now funds five regional care coordination contractors. Contractors work in their region's primary care sites to ensure the linkage of children to specialized medical services, as well as respite and community resources. The care coordinator contractors are also expected to support practices in their regions that are implementing medical home principles. There are currently 32 medical homes connected to the CT MHI for CYSHCN. The CT MHI for CYSHCN continuously recruits medical homes (primary care practices) to assist in identifying children with special health care needs (by utilizing the CAHMI CSHCN Screener(c)) as well as to distinguish the complex needs involved in supporting CYSHCN.

CT will modify the American Academy of Pediatrics (AAP) and National Center for Hearing Assessment and Management (NCHAM) developed "Universal Newborn Hearing Screening (UNHS), Diagnosis, and Intervention: Patient Checklist for Pediatric Medical Home Providers" (see Attachments – Checklist for Pedi MHs_draft) and make it available to medical homes within the system as a tool to ensure infants seen in their practice have their hearing screened by one month, receive appropriate and timely follow-up testing when indicated (by three months of age following a failed newborn hearing screening), and are referred to Birth to Three and receive services (by six months of age). Additionally, CT will develop accompanying guidelines modeled after Rhode Island's "UNHS, Diagnosis, and Intervention: Guidelines for Rhode Island Pediatric Medical Home Providers" flow chart/diagram to provide an at-a-glance outline of the

EHDI process in CT, best practice recommendations, and available resources and services in the state.

Objective 2.2: In order to integrate the EHDI and CYSHCN Programs' data infrastructure, the CYSHCN Access database will be transitioned to the new state-of-the-art application (called MAVEN) through the DPH's existing contract with Consilience Software by 8/31/2010. The DPH CYSHCN Program uses a Microsoft Access database to collect information on clients receiving services through the CT MHI for CYSHCN. DPH epidemiology staff trained the five care coordination contractors to use the database and continues to offer technical support to these centers. This database remains the primary data component of the Medical Home Initiative. There are several limitations to the existing Microsoft Access application used by the CYSHCN Program: 1) the database is stored locally at 10 different sites, thus making data collection and compilation time consuming; 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; and 4) as the database grows in size the operating functions will become slow and cumbersome.

In the Fall 2008, the CYSHCN Program added fields to their Access database to collect diagnosis specific related to hearing loss and hearing loss risk, including fields to collect the name of the child's audiologist, the test date, and the conclusion of the evaluation. The program Epidemiologist, Johanna Davis, educated contractors about these fields when she conducted data-related site visits. Currently children who do not pass the hearing screening and do not have documented follow-up results within six months of their date of birth (or in other words are at risk of being lost to follow-up), can be manually compared to the CSHCN data set to determine if the family is linked to a medical home affiliated with the CSHCN community-based system of care. This offers an alternative method of obtaining information on the status of their hearing; however, an integrated data system would automate and expedite this process to facilitate more timely follow-up.

Agency-wide efforts are underway to move older systems to a state-of-the-art Public Health Informatics Network (PHIN) platform called Maven, which offers customizable, secure web-based reporting features (see Attachments – Letters of Support). Consilience staff are working with the following programs: EHDI, Laboratory Newborn Screening, Birth Defects, childhood lead poisoning prevention and control, immunizations, vaccine preventable disease surveillance, and environmental public health / occupational health, as part of the agency-wide initiative to reduce data information silos; maximize the use of shared hardware and software to ultimately reduce related costs; use the latest technology; offer consistent IT database support; and include strict security procedures, firewall protection, and recoverability features. The DPH Maven project was undertaken to enhance the EHDI Program's tracking and surveillance system to allow for accurate reporting on the status of every occurrent birth throughout the EHDI process as well as to evaluate 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.

Transitioning the CYSHCN database to Maven would involve the following steps: modeling, which involves working with the Consilience developer to model the required business needs and data elements; implementing workflows to manage the data; creating print templates within

the application and a roster import; designing canned reports; migrating existing data; and ongoing maintenance moving forward. This summer, Johanna Davis, the Epidemiologist who works with the CYSHCN Program, will be trained to perform the configurations in Maven in order to serve as a local resource for the EHDI, Lab NBS, Birth Defects, and CYSHCN instances in the application.

Maven is a web-based application and therefore is accessible to multiple reporting sources. Beyond the short-term needs of the Maven Project, DPH plans to implement Maven as a secure web-based method for pediatric health care providers to access the newborn records of children in their practice. Once Maven is set up to be utilized in this way, primary care providers would have the ability to run regular reports listing children who did not pass the hearing screening and for whom follow-up is needed. Additionally, reports could be generated on children with risk indicators for hearing loss who need regular monitoring. Maven has the potential to be an excellent tool to ensure the provision of quality care.

Evaluation: Both Objectives 2.1 and 2.2 will be evaluated by interpreting EHDI data to determine whether an increasing number of infants receive follow-up testing by three months of age from year to year and whether the overall project goal of 90% follow-up is attained.

Goal 3: Promote family-professional partnerships within the CT EHDI system to ensure family-centered, culturally and linguistically competent care for all Connecticut families, including families of infants who do not pass newborn hearing screening, and to inform efforts to reduce the number of infants lost to follow-up after failure to pass newborn hearing screening.

Objective 3.1: By 8/31/2010, develop, print, and distribute parent survey postcards to the 31 birth facilities in the state in order to evaluate their satisfaction and understanding of the EHDI process and evidence of a family-centered, culturally and linguistically competent system of care. Parents of children with special health care needs including a child(ren) with a hearing loss, community providers, and DPH Epidemiologists will assist in writing the survey questionnaire, identifying the best methods for dissemination and collection, and evaluating the survey results. The survey will utilize components of the Family-centered Care Self-Assessment Tool, 2008, developed by Family Voices with funding from the Maternal and Child Health Bureau (MCHB) to increase awareness of family-centered care and provide an organized way for health care settings to assess current areas of strength and identify areas for growth, plan future efforts and track progress in the areas of family/provider partnership, care setting practices and policies, and community systems of services and supports. The survey will be translated into multiple languages and will ask parents for feedback on supporting the family as the constant in the child's life, giving a diagnosis, and ongoing care and support along with how well the screener did their job, how well the results were explained to them, and their overall satisfaction with the hearing screening process as well as their intended follow-up practices. The survey results will be used to improve or expand initiatives aimed at reducing loss to follow-up rates and to revise EHDI educational materials as appropriate.

Objective 3.1 compliments proposed activities under the currently funded HRSA *Reducing Loss to Follow-Up* project, which included distributing a parent survey to a random group of families via mail. Additional funds from this proposal would allow EHDI staff to take this a step further

and implement parent survey cards at the hospital-level. Hospital staff would be instructed to ask parents to complete the comment cards and rate how well the screener did their job as well as their intended follow-up action, and then submit the postcard prior to discharge or directly to DPH via mail at their own expense (cards would be anonymous but labeled by hospital in order to identify feedback by facility). This would utilize a strategy commonly used in customer service and may motivate parents to complete follow-up if they feel that another individual is being affected directly by their actions. DPH Epidemiologists will assist in writing the survey questionnaire, identifying the best methods for dissemination and collection, and evaluating the survey results.

Evaluation: If surveys are distributed to 80% of CT births (0.8 x ~ 42,000 = 33,600), a 30% response rate would mean DPH was in receipt of 10,080 surveys, which seems unlikely. A 10% response rate would be acceptable, which would mean DPH has to receive 3,360 surveys per year.

Objective 3.2: EHDI staff will solicit parent involvement and feedback in the EHDI process in order to identify opportunities and strategies to motivate families to pursue timely follow-up after their baby fails to pass the newborn hearing screening, initially by 8/31/2010 and ongoing thereafter. The current capacity of the DPH to offer culturally sensitive, linguistically competent education to families and resource information to health care providers will be enhanced by implementing the National Center for Cultural Competence, Georgetown University Center for Child and Human Development, A Guide for Advancing Family-Centered and Culturally and Linguistically Competent Care, 2007, which provides strategies and approaches to integrate family-centered and culturally linguistic competences into program policy. Parent input will be sought regarding information exchange and social marketing, an area of focus that suggests strategies for exchanging information and conducting social marketing initiatives that integrate family-centered care and cultural and linguistic competences into practices and increases awareness among families. The focus of information exchange and social marketing will allow for opportunities to share the benefits of family-centered care and cultural and linguistic competence such as improved quality of care, better health outcomes, increased satisfaction with care, enhanced relations between patient-provider, reduced risk of medical errors attributed to language/cultural barriers, and reduced racial, ethnic, and geographic disparities. Examples of some materials that will be reviewed will include but not be limited to the following; hearing results notification guidelines, parent letters, and other educational materials developed and distributed by the EHDI Program. Parents who can serve in this capacity will be identified using family organization resources connected to the CYSHCN Program, CT MHI for CYSHCN, and Birth to Three (CT's IDEA Part C early intervention program).

A major focus of the DPH CYSHCN program is assuring family/consumer involvement and cultural and linguistic competence in program and policy development and CYSHCN staff has significant experience engaging families of children and youth with special health care needs in this process. CT DPH staff has long supported the concept of family-centered care and cultural and linguistic competence as directed by the Maternal and Child Health Bureau through National Performance Measures and resources available through the Maternal and Child Health Bureau National Centers including the Family Voices National Center for Family professional Partnership (NCFPP), the National Center for Cultural Competence (NCCC), and the National

Center for Hearing Assessment and Management (NCHAM). These National Centers provide leadership on implementing the core component of a system of care for children and youth with special health care needs working to increase the capacity of families to partner in decision making at all levels, contribute to the knowledge on cultural and linguistic competency within systems and organizations, and assist in the development and operation of sustainable statewide Early Hearing and Detection Intervention (EDHI) systems.

From the AAP policy statement on Family-Centered Care and the Pediatrician's Role stating that, "family-centered care is based in the understanding that the family is the child's primary source of strength and support." The following definition of family-centered care is shared, "family-centered care is an approach to health care that shapes health care policies, programs, facility design, and day-to-day interactions among patients, families, physicians, and other health care professionals."

Additionally, the Connecticut Birth to Three System has three hearing specialty centers that specialize in working with infants and children who are deaf and hard-of-hearing. All three-specialty programs have informal parent groups that help connect parents of young children with hearing impairment with other families receiving services. These unofficial Birth to Three parent groups would offer a captive audience for reviewing and providing feedback on EHDI materials. Lastly, the CT Family Support Network works closely with both the DPH CYSHCN Program and Connecticut Birth to Three System and is part of the CT Family Support Council, which was established by statute in 1994 to assist the various state agencies that administer or fund family support services to: establish a comprehensive, coordinated system of family support services, use existing state and other resources efficiently and effectively, identify and address services that are needed for families of children with disabilities, and promote state-wide availability of such services.

According to the National Survey of Children with Special Health Care Needs (NS-CSHCN), 2001, there are significant disparities related to race and ethnicity in how families perceive the services and supports they receive for their children (US Department of Health and Human Services, 2004). When compared to White children with special health care needs, Black and Hispanic children with special health care needs are more likely to have families who report disparate experiences in the health care delivery systems. Other findings include the following: almost half of Hispanic and Black children with special health care needs have families who reported that the services that they receive are not family–centered; more than half of the Hispanic (55.9%) and Black (51.6%) families of children with special health care needs have families who report that they do not receive services for their children in a medical home, and more than half of the Hispanic and Black children with special health care needs have families who report that they do not have adequate insurance for their children.

Connecticut is a relatively small state of about 5,000 square miles and 3.5 million people and is continuing to become more diverse with the Hispanic, Asian, and Black population increasing an estimated 50, 68, and 13 percent respectively since the 1990 census, while the white population decreased 4%.(Maternal and Child Health Services Title V Block Grant, 2009). Connecticut is land of contrasts; wealthy suburbs surround cities that are among the poorest in the nation. For example nowhere in the country are economic disparities greater than Hartford, CT

(CREC,2008). In a state ranked second in the country in per capita income, Hartford has one of the lowest per capita incomes in the nation (US Bureau of Economic Development, 2008). When reviewing Connecticut's maternal and child health indicators, racial and ethnic disparities are quite evident, and reducing the disparities remains a major challenge facing the public health community. (Maternal and Child Health Services Title V Block Grant, 2009) The impending shift in demographics make up of Connecticut's population will continue to change according to the Connecticut State Data Center that estimate the percentage of Hispanic residents will increase from 10.9 % in 2009 to 20.4% in 2030.

The National Center Cultural Competence defines cultural competence as requirements for an organization that include a congruent, defined set of values and principles, demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally and linguistic competence as the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by a diverse audience, including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities, and must have policy, structures, practices, procedures, and dedicated resources to support this capacity such as bilingual/bicultural staff, cross-cultural communication approaches, and cultural brokers. An emerging body of evidence documents the role and efficacy of cultural and linguistic competence in (1) increasing access to, and the acceptance of, care; (2) improving quality and safety in the provision of care; and (3) reducing disparities in the delivery of health and mental health care services and outcomes for racially and ethnically diverse populations. (National Center for Cultural Competence, A Guide for Advancing Family-Centered and Culturally and Linguistically Competent Care, 2007)

Objective 3.2 compliments an objective added to CT's non-competitive HRSA continuation of funding application in which funds were allocated toward a contract with an individual or organization to enhance parent involvement in the CT EHDI process and to improve parent-to-parent support and information availability for families of children with hearing loss in CT. This can be accomplished either through the creation of a formalized parent support group or through parent advocacy training workshops. The intent is to address the limited availability of parent support specifically geared toward families of children who are deaf or hard of hearing and the limited amount of parent involvement in the CT EHDI system overall in order to create a more family-centered system.

Evaluation: Based on the results of the parent surveys that will be distributed over the next three years, results would demonstrate increasing parent satisfaction with the newborn hearing screening process and the materials and information provided at the time of referral. Additionally, 90% of infants who fail the newborn hearing screening will receive audiological follow-up.

WORK PLAN

Goal 1: To implement innovative educational initiatives to supply health care providers with the knowledge and information necessary to support and encourage families to complete timely follow-up after their baby fails to pass the newborn hearing screening.						
Steps/Activity	Indicators/Measures	Outcome(s)/Output(s)	Responsible Party	Data Source	Start Date	Due Date
Objective 1.1: By 3/31/2010, educational initiatives targeting a reduction in loss to follow-up rates between hospital screening and audiologic diagnosis will be implemented at the hospital-level.						
1.1.1 Develop and distribute scripts to hospital staff for delivering verbal newborn hearing screening results to parents in the hospital	Each hospital will individually demonstrate improvement in loss to follow-up rates between 2009 and 2011	Subsequent hospital program surveys will indicate that these scripts were adopted	EHDI Coordinator (A Mirizzi), Nurse Consultant (K Britos-Swain)	Copies of scripts & program surveys; EHDI database	9/1/2009	3/31/2010
1.1.2 Write and disseminate a quarterly tips email to provide Nurse Managers with regular reminders regarding EHDI best practices to share with staff	Each hospital will individually demonstrate improvement in loss to follow-up rates between 2009 and 2011	Subsequent hospital program surveys will indicate that Nurse Managers found these tips helpful and shared them with staff	Nurse Consultant (K Britos-Swain)	Copies of emails sent; EHDI database	By 12/31/2009	Ongoing (at least quarterly)
Objective 1.2: By 8/31/2010, the Child Health and Development Institute of CT (CHDI) will develop an EPIC (Educating Practices in the Community) Module on early hearing detection and intervention in order to lead to improved quality of care related to hearing loss and risk indicators for hearing loss among pediatric-age patients in the primary care setting.						
1.2.1 Fully executed contract will be in place with CHDI to begin EPIC module development process	Signed-contract	DPH will negotiate contract terms with CHDI for module development	Nurse Consultant (K Britos-Swain)	DPH Contracts & Grants Mgmt Sect	9/1/2009	10/31/2009
1.2.2 Develop EPIC module on EHDI in collaboration with pediatric experts and community services providers	EHDI module is shared with DPH at various stages of development until a final product is completed	Final product: EHDI module that can be presented to pediatric and family medicine practices	CHDI	Contract deliverables	11/1/2009	2/28/2010

1.2.3 Present EPIC EHDI Module to pediatric and family medicine practice teams (RNs, MDs, and office staff)	90% of infants who fail the newborn hearing screen will receive audiological follow-up	Primary care practices will ensure ongoing monitoring of child's hearing status in the medical home	CHDI	CHDI final contract report	3/1/2010	8/31/2010

Goal 2: To build on the established Children and Youth with Special Health Care Needs (CYSHCN) system and infrastructure in Connecticut to facilitate timely follow-up for infants who do not pass newborn hearing screening.						
Steps/Activity	Indicators/Measures	Outcome(s)/Output(s)	Responsible Party	Data Source	Start Date	Due Date
Objective 2.1: By 4/30/2010, the five Connecticut Medical Home Initiative for CYSHCN care coordinator contractors will be equipped with tools to integrate early hearing detection and intervention best practices within their community-based system of care.						
2.1.1 Modify AAP/NCHAM *UNHS, Diagnostic, and Intervention: Patient Checklist for Pediatric Medical Home Providers* and adopt revisions in CT medical homes	Increase percentage of newborns who receive follow-up by 3 months of age incrementally each year; 90% of infants who fail the newborn hearing screen will receive audiological follow-up	Mechanism to assist in the tracking and follow-up of infants who require ongoing audiological follow-up.	HPA (A Gionet)	EHDI database	9/1/2009	4/30/2010

2.1.2 Develop flow diagram to accompany checklist outlining CT EHDI process and resources	Increase percentage of newborns who receive follow-up by 3 months of age incrementally each year; 90% of infants who fail the newborn hearing screen will receive audiological follow-up	Primary care provider will ensure ongoing monitoring of child's hearing status.	EHDI Coordinator (A Mirizzi)	EHDI database	9/1/2009	4/30/2010
Objective 2.2: In order to integrate the EHDI and CYSHCN Programs' data infrastructure, the CYSHCN Access database will be transitioned to the new state-of-the-art application (called MAVEN) through the existing contract with Consilience Software by 8/31/2010.						
2.2.1 Work with Consilience Software to model CYSHCN data elements, design workflows, reports, and print templates, and test after data migration and during staging.	Configurations will be tested in the Maven staging environment hosted at DoIT; once all changes are complete and historical data migrated, the CYSHCN instance will be moved to production.	The successful completion of the configuration of the CYSHCN programs in the Maven application; the successful conversion of 100% of the legacy data to Maven; and the ability of the programs to access the data and utilize all present report and query functions	Consilience Software consultants; Maven Project Team: DPH Business and Technology partners – including CYSHCN program and epidemiol-ogy staff (primary: J Davis)	CYSHCN Access database and Maven instance	9/15/2009	4/30/2010
2.2.2 Transition 10 current sites to the 32 MHs to utilize Maven CYSHCN web-based	100% of legacy data will be converted; All 32 MHs will	Integration of EHDI and CYSHCN data infrastructure to achieve	CYSHCN Epidemiolo gist (J	CYSHCN Maven instance	5/1/2010	8/31/2010

application	have user accounts and demonstrate the ability to enter data in Maven	timely and appropriate follow-up	Davis)			

Goal 3: Promote family-professional partnerships within the CT EHDI system in order to inform efforts to reduce the number of infants lost to follow-up after failure to pass newborn hearing screening.						
Steps/Activity	Indicators/Measures	Outcome(s)/Output(s)	Responsible Party	Data Source	Start Date	Due Date
Objective 3.1:By 8/31/2010, develop, print, and distribute parent survey postcards to the 31 birth facilities in the state in order to evaluate their satisfaction with and understanding of the EHDI process						
3.1.1 Design parent comment/survey cards, print postcards, and distribute cards to hospitals based on annual birth count	100% of hospitals receive survey cards	Mechanism to solicit ongoing parent feedback and for quality assurance for hospital programs	EHDI Coordinator (A Mirizzi), CYSHCN Epidemiologist (J Davis)	Copy of survey cards	9/1/2009	1/31/2009
3.1.2 Analyze results and share feedback with individual facilities for quality assurance purposes	100% of hospitals will distribute the survey; 10% response rate will be attained	The survey results will be used to improve or expand initiatives aimed at reducing loss to follow-up rates and to revise EHDI educational materials as appropriate.	EHDI Coordinator (A Mirizzi), CYSHCN Epidemiologist (J Davis)	Compilation of paper survey responses	3/1/2010	Ongoing
Objective 3.2: EHDI staff will solicit parent involvement and feedback in the EHDI process in order to identify opportunities and strategies to motivate families to pursue timely follow-up after their baby fails to pass the newborn hearing screening, initially by 8/31/2010 and ongoing.						
3.2.1 Identify parents to review EHDI program and educational materials	90% of infants who fail the newborn hearing screen will receive audiological follow-up	EHDI System in CT will be more family-centered	HPA (A Gionet)	EHDI database	9/1/2009	Ongoing

3.2.2 Identify mechanism to continue parent participation in reviewing EHDI program development	90% of infants who fail the newborn hearing screen will receive audiological follow-up	EHDI System in CT will be more family-centered	HPA (A Gionet)	EHDI database	9/1/2009	Ongoing

RESOLUTION OF CHALLENGES

Although the proposed activities complement current initiatives underway in the CT EHDI system, there are a number of challenges posed to the successful implementation of this project. The challenges anticipated in assuring that all infants are screened at birth and that those who fail the screening receive timely follow-up testing are challenges that are ongoing. Barriers exist in tracking infants who do not pass newborn hearing screening and are in need of follow-up testing. Various factors contribute to this challenge, such as locating those infants with name changes, a change in the PCP, and/or address changes after birth. This is an ever-present obstacle in locating children in any screening program, and is best resolved through diligent tracking. This problem is also curbed by the NSS CHP database link with 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, lost to follow-up rates have improved significantly in CT. EHDI staff also work with Immunization staff to consult a child's immunization record in order to 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. In a recent reorganization, the Immunizations Program joined the EHDI Program in the DPH Family Health Section, which will present additional opportunities for collaboration.

Goal 1: Implement innovative educational initiatives to supply health care providers with the knowledge and information necessary to support and encourage families to complete timely follow-up after their baby fails to pass the newborn hearing screening. 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. The proposed objectives/activities include scripting verbal delivery of newborn hearing screening results to parents and frequent reinforcement of EHDI best practices through quarterly "tips" emails to Nurse Managers. Some barriers may be convincing Nurse Mangers of the benefit of these tools; however, the EHDI database will be transitioned to the Maven application within the earlier part of grant year 1, which will give EHDI staff face-to-face contact with Nurse Managers to highlight these strategies. Additionally, its an excellent conclusion to the recent program survey and will demonstrate that DPH did in fact do something with the information gathered. CHDI has demonstrated success in implementing EPIC in the state. One potential downfall may be the feasibility of scheduling presentations with medical practices; however, the CT MHI for CYSHCN offers a target audience of providers and the number of medical homes connected to the program continues to grow.

Goal 2: To build on the established Children and Youth with Special Health Care Needs (CYSHCN) system and infrastructure in Connecticut to facilitate timely follow-up for infants who do not pass newborn hearing screening. Potential barriers to implementing the Patient Checklist and flow diagram may include the perceived low incidence of hearing loss among children, but coupled with other CYSHCN educational efforts and the EPIC EHDI module, greater provider receptiveness and openness is anticipated. It is also expected that the new CYSHCN Maven application will be embraced as an easily accessible system with advanced reporting capabilities that reduce the time required for state reporting and assist with implementing quality assurance measures.

Goal 3: Promote family-professional partnerships within the CT EHDI system in order to inform efforts to reduce the number of infants lost to follow-up after failure to pass newborn hearing screening. Program staff have conducted family surveys via mail in the past to assess the satisfaction level with the program and to identify areas in need of improvement. Past problems encountered include: address changes (many surveys came back: returned to sender), poor sample size, poor response rates, and underdeveloped questions that appeared to confuse families completing the surveys. It will be important to pilot the survey with families who partner with the EHDI Program moving forward. Existing CYSHCN and Birth to Three family ties are viewed as a helpful advantage to facilitating the success of these objectives.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Mark Keenan, RN, MBA, will now serve as the Project Director. Mr. Keenan, Supervising Nurse Consultant with the Department of Public Health, is Connecticut's Title V Children and Youth with Special Health Care Needs Director. He provides supervision to the CT Children and Youth with Special Health Care Needs Program (including the Medical Home Initiative for CYSHCN which provides care coordination services to more than 6,000 children with special health care needs through 32 medical homes), the State Sickle Cell Program, and the newborn Early Hearing Detection and Intervention programs. Mr. Keenan has over twenty-five years of experience in the fields of developmental disabilities and special health care needs. Mr. Keenan has well-established relationships with collaborating stakeholders through service on numerous councils and work groups including the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities (UCEDD) Consumer Advisory Council.

Amy Mirizzi, MPH, CPH, Health Program Associate, was hired in 2005, and was primarily responsibility for EHDI tracking and surveillance, which includes: database maintenance and management, database design, and data analysis and interpretation; program monitoring; and the development and maintenance of quality assurance techniques in order to meet program goals and objectives and monitor hospital compliance with CT's universal newborn hearing screening statute. Since June 2008, Ms. Mirizzi has served as the EHDI Coordinator for the state and is a member and past chair of the, the CT EHDI Advisory Board, a member of the Commission on Deaf and Hearing Impaired Advisory Board, and a member of the Directors of Speech and Hearing in State Agencies. Ms. Mirizzi maintains a strong partnership between DPH and CT birth hospitals, audiologists, the Department of Developmental Disabilities - Birth to Three System, and the CSHCN program. Ms. Mirizzi 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, and ongoing program evaluation. Ms. Mirizzi 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.

Kathryn Britos-Swain, RN, MSN, Nurse Consultant, began working with the EHDI Program in June 2008. Ms. Britos-Swain commits a portion (40%) of her time to EHDI activities, but is obligated to other programs within the Family Health Section as well. She assists with

educational and outreach projects and consults on overall program development as well as providing technical assistance to CT's 31 birth facilities on issues related to newborn screening protocol and electronic reporting requirements and performs duties related to tracking and follow-up.

Ann Gionet, part-time Health Program Associate and Family Advocate, will begin working full-time hours; 0.43 of her time (15 hours/week) will be devoted to EHDI activities. Ms. Gionet has worked in the Children & Youth with Special Health Care Needs Program for the last for 14 years. She is very knowledgeable about all aspects of the program, and participates in program design and implementation activities. A major focus of the CYSHCN program is assuring family/consumer involvement in program and policy development, and Ms. Gionet has significant experience engaging families in this process through mentoring and culturally appropriate supports as well as educating staff to engage consumer participation, support families, and arrange for financial support. Ms. Gionet has participated in numerous family / professional partnership workshops and conducted presentations on the importance of family-centered care and fostering family professional / partnerships. Ms. Gionet is well positioned to facilitate the integration of CYSHCN Program activities and EHDI Program activities and will be a valuable resource to improve parent involvement in the CT EHDI system.

Furthermore, Johanna Davis, Epidemiologist 3, will oversee the transition of the CYSHCN database to Maven. Ms. Davis is currently working with the EHDI Program on the Birth Defects Registry portion of the NBS transition to Maven. She created and maintains the CYSHCN Access database, which currently includes 10 different Access data sets coming into the state for analysis. During the summer of 2009 she will be going through a week long training to become a MAVEN administrator. This will enable her to perform basic system updates and enhancements to workflows and reports, along with some basic troubleshooting in order to resolve system problems that can arise.

The CT EHDI program has a published an array of educational and informational materials for both families and providers that support all aspects of the EHDI Program. DPH developed a brochure for families titled, "Listen Up!" that explains the hearing screen and outlines developmental milestones. It is given to families by each birth facility at the time of birth. A second brochure titled, "A Parents Guide to Diagnostic Hearing Testing of Infants" was developed for families of babies who do not pass the newborn hearing screen. It explains the purpose and importance of taking their 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. EHDI Program staff in collaboration with the CT EHDI Advisory Board also developed and distribute a resource, called: "What YOU Need to Know About Providing Health Care for Infants & Young Children with Hearing Loss," to PCPs, EI providers and medical home/CSHCN care coordination networks, which includes information about risk factors for hearing loss in childhood and appropriate monitoring and follow-up protocol.

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. The training consists of seven individual sessions and covers both genetic and metabolic screening as well as newborn hearing screening. Free CMEs and CEUs are offered upon successful completion of one or all of the sessions. To date, over 290 licensed health care providers from across the United States have completed the training.

The CT IDEA Part C EI Program, Birth to Three, 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 various stages of the proposed project 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 **t**he 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 EHDI program and epidemiological staff and are outlined under each specific goal in the Methodology section as well as in the Work Plan. Overall, based on the strategies outlined in this proposal, CT aims to see loss to follow-up rates reach 10% or less by 8/31/2012. Individual hospital follow-up rates will be analyzed every six months beginning 9/1/2009 by comparing the number of referrals to the number of infants receiving audiological follow-up. CT delineates follow-up under six categories: none, in progress (documented contact with a center but inconclusive results), within normal limits, hearing loss, refused and deceased. The seventh category is "Lost" and is applied when all means of tracking the family have been exhausted. EHDI staff will also monitor timeliness of follow-up based on CDC data categories: before 3 months of age, between 3 months and 6 months of age, and after 6 months of age – with the intent of seeing the number of infants in the latter categories move to the before 3 months of age category.

ORGANIZATIONAL INFORMATION

The DPH has the organizational experience and capability to coordinate and support planning, implementing, and evaluating a comprehensive approach to meet the goals and objectives outlined in the project.

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). Other programs in the FHS include Immunizations (as of 1/5/09), Children with Special Health Care Needs, School and Adolescent Health (school-based health centers), Community Health Centers, Sickle Cell Disease Education, 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.

In accordance with the Health Resources and Services Administration (HRSA) definition of children and youth (zero to less than twenty-one years of age) with special health care needs, the CT DPH CYSHCN Program supports the special health care needs of those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. The CT CYSHCN Program has developed a CT Medical Home Initiative (MHI) for CYSHCN, which is a community-based system of care for children and youth with special health care needs. It was designed to enable CYSHCN to receive coordinated, ongoing, comprehensive care in their local communities. The two primary goals include: (1) increase the number of CYSHCN that receive family-centered, coordinated care through community-based health care systems using Title V funds and (2) improve the availability of programmatic and health care service data on CYSHCN from which to evaluate the system and develop quality improvement programs. The DPH CYSHCN Program has significant experience with implementing systems of services for children with special healthcare needs and their families.

Operating under the President' s New Freedom Initiative: Fulfilling America's Promise to Americans with Disabilities charge, DPH is committed to developing and implementing a plan to achieve appropriate community-based systems for CYSHCN and their families/caregivers (as specified in "Delivering on the Promise" under Solution III C, New Freedom Initiative).

Establishment of this system is reflected in: 1) Family Participation and Satisfaction, 2) Access to Medical Home, 3) Access to affordable insurance, 4) Early and continuous screening, 5) Easy-to access community-based service systems, and 6) Services necessary to transition to adulthood. The DPH works with three contractors to provide services in the following categories: care coordination; management of extended services and respite funds; and provider and consumer outreach and education. The care coordination service contractors aim to enhance statewide implementation of a comprehensive, accessible, and coordinated system of care for families of CYSHCN. The five care coordination medical home networks are: the Stamford Health System serving Southwest CT, the Coordinating Council for Children in Crisis in New Haven serving South Central CT, Saint Mary's Hospital serving Northwest CT, United Community and Family Services, Inc. in Norwich serving Eastern CT and CT Children's Medical Center in Hartford serving North central CT. Each network is affiliated with several clinical practice sites – there are currently 32 medical homes statewide. The Connecticut Lifespan Respite Coalition (CLRC) administers the respite and extended services funds. The Child Health & Development Institute (CHDI) of Connecticut provides statewide outreach and culturally competent education to pediatric primary care providers (using the EPIC model) and families on the concept of medical home for children and youth with special health care needs. Family support services are implemented through a subcontract with the CT Family Support Network and include providing assistance and culturally appropriate education to families of CYSHCN to enable families to acquire the skills necessary to access needed medical and related support services, which in turn empowers them to become competent advocates for their children. The CT Family Support Network is a network of families who have children with disabilities. They are parents interested in helping other parents to find the supports they need. The Network was created by the Connecticut Family Support Council, a legislatively established partnership of parents and professionals working to improve supports for families of children with disabilities.

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 have been greater than 99% for the past 4 years.

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, an otolaryngologist, and other community-based representatives who work with the deaf and hearing impaired population. 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.

The DPH has had a Memorandum of Agreement (MOA) with the Department of Developmental Services (DDS), lead Agency for IDEA Part C, since 1999 (revised 2009) to share program data on infants identified through EHDI. This MOA allows the two agencies to collaborate on a process that provides early identification and habilitative treatment of infants with hearing

impairments by permitting the exchange of data between DDS and DPH to assure infants with diagnosed hearing loss are enrolled in the Birth to Three System.

CT has legislation in place that mandates audiologists and other health care providers 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, called Child Development Infoline (CDI). CDI Care Coordinators are able to refer families to services and follow-up with families to assure needs have been met. CDI caseworkers assess the caller's situation, and make referrals to the CT Birth to Three System, Help Me Grow, Preschool Special Education, and/or the Medical Home Initiative for CYSHCN.

As described previously, 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 this 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. 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. Agency-wide efforts are underway to move older systems to a state-of-the-art Public Health Informatics Network (PHIN) platform called Maven, described previously. 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. Maven will need to “go live” at all 31 birth facilities simultaneously to prevent data overlap. Before the final data set is migrated and Maven is implemented across the state, extensive database testing will be performed. 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 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.