DUNS Number 807853791

PROJECT IDENTIFIER INFORMATION
Project Title: UNHS Tracking, Surveillance and Integration
Project Number: CFDA #93.251
E-mail Address: donna.maselli@po.state.ct.us

PROJECT ABSTRACT
Program Description**:** The purpose of this project is to enable Connecticut (CT) to improve the state mandated Universal Hearing Screening and Intervention (UNHS) program, which began on July 1, 2000, to assure quality developmental outcomes for infants identified with hearing loss (HL). This includes assuring that all infants are screened before hospital discharge 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 providers and families. This project addresses preventative and primary care services for infants and children with special health care needs. There are five overt challenges to this project: 1) there is no formalized program to track and locate infants that may be lost to follow-up; 2) early intervention services are lacking for infants with a unilateral hearing loss or bilateral hearing loss that is less than 40 dB; 2) there is no mechanism for providing a linkage to a medical home, follow-up or resources to those infants who screen negative, but are at risk for developmental delay due to mild to moderate, unilateral loss or other risk factors; 4) hospitals with neonatal intensive care units (NICU's) vary in their methods and capacity to perform newborn hearing screens; 5) to increase the current capacity of the DPH to offer culturally sensitive, linguistically competent education to families and resource information to health care providers. Each of these challenges is addressed under methodology.

Goals:

This project will address the following goals: **Goal** 1: To establish a continuous, formalized program to track infants lost to follow-up. Objective 1: By December 1, 2005 a Health Program Assistant will be hired to assist in tracking infants who were discharged without a hearing screen or who were identified as at risk for hearing loss from the initial screen and did not receive audiological follow-up. By April 1, 2006 a formalized child find program will be established. By September 1, 2006 the screening rates will increase to 99% and the lost to follow-up rates will decrease to 10%. **Goal 2**: To assure that all hearing impaired infants receive ongoing monitoring and are linked to a medical home to assure quality developmental outcomes. Objective 2: By March 1, 2006, DPH will contract with the three statewide early intervention audiology centers that specialize in working with infants and children who are deaf or hearing, impaired to provide ongoing monitoring and follow-up of infants with hearing loss who are not eligible for EI services. By July 1, 2006 90% of families of infants with unilateral hearing loss or a bilateral hearing loss of <40db will be linked to a medical home, providers will be educated on developmental milestones, and families will be educated on environmental modifications that can facilitate hearing and speech development. **Goal 3:** To have a mechanism in place to provide ongoing follow-up to infants who screen negative, but are identified as at risk for hearing loss. Objective 3: By July 1, 2006 UNHS staff will have a plan and protocols developed to implement a follow-up monitoring program for the children at risk for hearing loss who do not qualify for EI services. By July 1, 2006 the CT Newborn Hearing Screening Task Force will

outline recommendations for follow-up monitoring of infants and children at risk. By August 1, 2006 hospital newborn screening staff in the 31 birth facilities will be educated on the identification of risk indicators in newborns and the importance of educating families about the importance of ongoing monitoring of these at risk infants. The Department of Public Health will develop informational materials pertaining to audiological follow-up and monitoring for these infants and will disseminate the information to all health care providers by September 1, 2006.
Goal 4: Ensure that all birthing facilities with NICU's provide standardized newborn hearing screening prior to discharge. Objective 4: Provide funding to the NICU's that do not have automatic brainstem response to purchase the equipment so that all high- risk infants will have an ABR screening conducted prior to hospital discharge. By March 1, 2006, 100% of all NICU's will have ABR screening equipment available to screen high-risk infants. By July 1, 2006 90% of all NICU infants will have an ABR screening before discharge. **Goal 5**: To provide informational and educational materials for families and health care providers on hearing screening, risk indicators, diagnostic and genetic evaluations and early intervention options. Objective 5: A resource guide will be developed to educate health care providers on all aspects of the UNHS program, and support services available for families of infants with hearing loss. A pamphlet will be developed for families with information on the availability of genetic testing in hearing loss. An educational conference will be held for audiologists to inform them about all aspects of the UNHS program and educate the on advances in genetic testing for infants with hearing loss. A pre and post-test will be given to evaluate knowledge gained. By November 1, 2007 the printed materials will be available for distribution and 95% of the Diagnostic Testing Centers will have participated in the educational conference.
Healthy People 2010: This project addresses the Healthy People 2010 objective of assuring that children with special health care needs and their families have access to appropriate, adequate and timely services that are family-centered, comprehensive, coordinated and culturally competent. This project involves population-based services that will serve women and children, including those from communities with limited access to comprehensive care.
Methods and Coordination: The goals and objectives outlined above will be met through several methods. The primary method will be to hire one additional UNHS program support person to assist in the tracking of infants lost to follow-up, assisting in assuring that communication exists between the family and primary care provider and that the child is linked to a medical home and to assist with other program functions as needed. Additionally, by providing the NICU's with ABR screening equipment CT will support the standardized screening statewide and assure that infants at highest risk receive an ABR screening. The methods will be cost-effective in that a comprehensive UNHS infrastructure is already in place. CT has a well-established UNHS Task Force that meets monthly and its members have expertise in infant hearing, diagnostics and intervention. The Task Force assists the DPH with the development of educational materials, training and inservicing of hospital staff, audiologists and health care providers and will support the development of any trainings or materials outlined through this project. CT has an ongoing working partnership with CT Birth-to-Three, which provides EI services for our children. The DPH, FHD manages the CSHCN program and is in the process of implementing the Medical Home Learning Collaborative. Through this initiative DPH is transitioning the service providers of children with special health care needs into the Medical Home concept. There will be five Regional Centers across the state that will provide support and assistance to the medical home providers in the region. **Evaluation Methods:** The Program Manager and support staff will evaluate the UNHS program at multiple points using the state

developed data management system. The infant's age at screening, method of screening, age and date of diagnosis and age and date of enrollment in EI will be tracked, as well as lost to follow-up rates. Infants with risk indicators will be tracked to assure that the family and PCP received information about follow-up. The infants with hearing loss who are not eligible for EI will be evaluated by the numbers who receive audiological follow-up every six months and by the numbers who develop progressive hearing loss. Satisfaction surveys will be mailed to a sample of parents and health care providers to evaluate the educational materials developed through this project.

Key Words: Universal newborn hearing screening, false-positive, diagnostic testing, , primary care providers, medical home, automated brainstem response (ABR), otoacoustic emissions (OAE), Birth-to-Three, early intervention (EI), lost to follow-up, population served, cultural competency, genetics.

Text of Annotation: The CT DPH will build on the established UNHS program to ensure that all infants are screened at birth prior to discharge, that infants receive prompt diagnostic testing by trained audiologists by two months of age, that eligible infants are enrolled in an EI program by four months of age and that all infants are linked to a medical home. This project will establish a follow-up program for infants with a unilateral or other hearing loss, who are not eligible for EI services and will establish a mechanism to locate infants lost to follow-up. Informational materials will be developed for families and health care providers to assist families in making an informed decision about treatment options available.

PROGRAM NARRATIVE

Purpose of the Project: Hearing loss is the most common occurring congenital disability and studies have shown that infants identified and enrolled into early intervention by six months of age, develop language skills commensurate with their hearing peers by the age of three. The overall purpose of the CT UNHS program is to ensure that all newborns are screened for hearing loss before hospital discharge, that diagnostic testing is conducted by two months of age, that infants with a diagnosed hearing loss are enrolled into early intervention by four months of age, and that steps are taken to minimize the infants who are lost to follow-up. In 2004, the average age of diagnosis of a child with a hearing loss in CT was 1.86 months and age at referral to early intervention was 2.37 months of age, well below the national goals.

The purpose of this project is to enable Connecticut (CT) to improve the state mandated UNHS program, which began on July 1, 2000, to assure quality developmental outcomes for infants identified with hearing loss. Specifically, this project will 1) establish a Child Find program to track infants that are lost to follow-up; 2) establish a follow-up monitoring system (already in place for infants with a bilateral, 40 dB or greater hearing loss) for infants with hearing loss who are at risk, but not eligible for early intervention services; 3) assure that all infants who screen negative, but are at risk for speech, language and developmental delays are linked to a medical home for ongoing monitoring and a family support network (infrastructure in place through Title V CSHCN program); 4) improve standardization of the screening protocols for UNHS at 4 hospitals with neonatal intensive care units, and provide screening equipment to those institutions requiring assistance in meeting the standards; 5) provide educational materials for health care providers and families of infants with hearing loss, to enhance informed decision making regarding treatment options.

Needs Assessment

Connecticut has a well-established early hearing detection and intervention program. Legislation was passed to provide UNHS to all newborns and the program was implemented on July 1, 2000. The Department of Public Health is the lead agency that administers the UNHS program. The DPH collects screening data from birth hospitals through an internet-based reporting system. Infants who are identified as a "refer" from the hearing screening conducted in the hospital are referred to one of the state's 18 designated Diagnostic Testing Centers for audiological follow-up and diagnosis. Infants with a diagnosed hearing loss are referred to the CT Birth-to-Three System, the state's EI provider. The DPH has a Memorandum of Understanding with the Department of Mental Retardation, lead Agency for Idea Part C, to share data between programs of infants identified through UNHS (see Appendix C, Memorandum of Understanding). CT has three EI audiology centers that specialize in infants who are deaf or hearing impaired. Infants are referred to EI at the time of diagnosis, with a 2004 average age of referral of 2.37 months.

Goal 1: CT had 42,543 births in 2004 and has 31 birth hospitals. All hospitals utilize a two-step screening program. Infants receive the first hearing screen using otoacoustic emissions (OAE) or automatic brainstem response (ABR) equipment. Infants that do not pass the first screening have the screening repeated before discharge using the ABR method. Infants who refer from the second screening are referred to one of 18 diagnostic testing centers for audiological follow-up. In 2004, 98% of all newborns received a hearing screen before hospital discharge. A total of 92.42% of the infants passed the first screen and 6.42% passed the second screen. There were sixteen infants or 0.04% of infants who were not screened and 12.6% who did not pass the first screen, and were lost to follow-up from screening. There were 356 (0.85%) of infants who

referred from the hearing screening at birth and of the 194 infants who went for follow-up, 47 (0.11%) were diagnosed with a hearing loss. There were 180 infants (0.44%) who were lost to follow-up from diagnostics.

Goal 1 of this project is to establish a continuous, formalized program to track infants lost to follow-up. The Newborn Screening program has two components: newborn hearing screening and laboratory newborn screening. Staffing for the UNHS program is presently 1 FTE Nurse Consultant who also serves as the Team Leader of the Newborn Screening program. To assist in tracking infants who were discharged without a hearing screen or who were identified as at risk for hearing loss from the initial screen and did not receive audiological follow-up, a Health Program Assistant will be hired. A formalized child find program will be established to locate the child and inform the primary care provider (PCP) of the need for screening and/or follow-up.

The CT UNHS program has an established internet-based data tracking system in place through which birth hospitals report demographic information and hearing screening results to the DPH. The Newborn Screening System (NSS) is linked with the Newborn Metabolic Screening Program and the Birth Defect Registry. The NSS has extensive report capabilities but the program does not have the staff to conduct the continuous tracking and follow-up. It is anticipated that with the hiring of a FTE staff person whose primary purpose is to conduct tracking that the screening rates will increase to 99% and the lost to follow-up rates will decrease to 15% by the end of year 1 of this project.

Goal 2 of this project is to assure that all hearing impaired infants receive ongoing monitoring and are linked to a medical home to assure quality developmental outcomes. In 2004, 47 infants were identified through UNHS with a diagnosed hearing loss. Of those 47 infants diagnosed, only 14 were eligible for EI services. Current CT early intervention (EI) eligibility

requirements provide services for children with a bilateral hearing loss, that is 40dB or greater in both ears. Children with a bilateral hearing loss that is mild (20-40dB) in one ear and any degree loss in the other ear, or children with a unilateral hearing loss, are not eligible for EI services. In 2004 there were 33 children with hearing loss who were not eligible for Birth-to Three services.

For young children, normal hearing is considered to be from 0-15 dB. Children with hearing loss in the 20-40 dB ranges can miss up to 40% of spoken language (Flexor, 1995). The softest sounds of speech are approximately 35dB, while the loudest are at 60dB. Infants with mild hearing loss (20 – 40 dB) will not have access to voiceless sounds such as /s/ and /t/, yet are able to hear the vowels. This may result in phonological and linguistic problems (Brackett, Maxon, Blackwell, 1993).

Children with unilateral loss experience inconsistent access to speech. The listening environment has a significant impact on speech, language and listening development. If there is middle ear disease in the normally hearing ear then loss will be bilateral. Speech and language development may be typical, but difficult listening conditions will have a disproportionate negative effect (Brackett, Maxon, Blackwell, 1993). By school age, a child with a mild hearing loss or with a unilateral hearing loss is 4.3 times more likely than a normally hearing child to perform at deficient levels on communication tests requiring abilities receptive language, vocabulary and storytelling (Bess, 1999). In one study of 1,218 students, 37% of the children with unilateral or mild hearing loss have failed at least one grade in school, compared with a failure rate of 3% for the district norm (Bess, Dodd-Murphy and Parker, 1998).

Connecticut's early intervention program serves children with developmental delays and does not serve "at risk" children. Prior to UNHS the average age of identification of children with hearing loss was 12-36 months. It was often the speech delays that prompted the testing

and identification of the hearing loss. Since the implementation of UNHS, the average age of diagnosis of a hearing loss has become increasing younger. In 2004 the average age of diagnosis in CT was 2.37 months of age, well before a child has developed speech and has evident language delays.

This project will establish a mechanism to provide ongoing monitoring and follow-up of infants with hearing loss who are not eligible for EI services. The anticipated benefits will be to monitor the child's hearing and speech development every six months so that intervention can be promptly implemented and that language delays can be averted, assure that each child is linked to a medical home, and that family education, support and advocacy are provided.

Goal 3: 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 2000 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 known risk indicators require hearing evaluations every six months until age three, at appropriate levels thereafter.

In 2003 the DPH added data collection fields for risk indicators in the NBS. Although the data is collected, the UNHS staff does not have the necessary report capability to identify which infants with risk indicators passed the hearing screen at birth. Plans are in place to enhance the UNHS report capability and capacity. In 2004, the birth hospitals reported 1,568 infants (3.7%) infants with risk factors for hearing loss. Goal 3 of this project is to establish a mechanism in provide ongoing follow-up to infants who screen negative, but are identified as at risk for hearing loss. A more plausible method of assuring follow-up is for patient education to be conducted at

the birth hospital. The Connecticut EHDI program currently lacks a formalized mechanism to monitor or recommend follow-up for infants with risk factors for hearing loss.

Goal 4: Connecticut has 31 birthing facility. The CT UNHS program goals are consistent with, the JCIH 2000 position statement benchmarks. Objective physiologic measures are employed to detect infants with hearing loss. Infants are screened at birth using otoacoustic emissions testing (OAE), either transient evoked or distortion product, and /or auditory brainstem response (ABR) testing. Both methods are non-invasive recordings of physiologic activity that underlie normal auditory function and are easily recorded in infants. OAE technology is used to detect inner ear or sensory hearing loss and measures response up to the cochlea. OAE can be reliably recorded in newborns in response to stimuli in the frequency range above 1500 Hz. OAE is sensitive to outer ear canal obstruction and middle ear effusion and may cause a false-positive screening result due to fluid or debris in the ear canal from birth.

Because OAE responses are generated within the cochlea, OAE does not detect auditory brainstem dysfunction.

With previous MCHB UNHS funding the DPH standardized screening throughout the state. Funding was provided to the seven hospitals that utilized OAE screening as the sole method, to purchase ABR screening equipment. The purpose was to provide the resources to hospitals to enable all infants that do not pass the first hearing screening, to have an ABR screening before discharge.

ABR screening methods reflect the activity of the cochlea, auditory nerve, and auditory brainstem pathways. When used as a threshold measure the ABR is highly correlated with hearing sensitivity in the frequency range from 1000 Hz to 8000 Hz.

A total of 6 CT hospitals have Special Care Nurseries and 11 have Neonatal Intensive Care Units (NICU's). An unanticipated problem has occurred in the larger hospitals where the NICU and well-baby nurseries are not in close proximity to one another, and/or one ABR screener is not sufficient and to screen the large volumes of infants. As a result, NICU infants are being discharged without having had an ABR screening. Through this project DPH will ensure that all birthing facilities with intensive care units provide standardized newborn hearing screening prior to discharge.

Goal 5: The successful mapping of the Human Genome in 2003 has created an explosion of clinically relevant knowledge that continues to expand as the functions of our 30,000 or more genes are identified. Over the past eight years, remarkable progress has been made identifying new hearing impairment loci and cloning new genes for deafness. According to the American College of Medical Genetics, at least 77 loci for nonsyndromic hearing loss have been mapped: 40 autosomal dominant, 30 autosomal recessive, and 7 X-linked. Information about these genes has revolutionalized our knowledge about the molecular processes involved in hearing and enhanced our understanding of how genetic alterations can lead to hearing loss. Geneticists play a major role in the management of infants with newly detected hearing loss by facilitating the establishment of an etiologic diagnosis.

A recent statewide needs assessment was conducted in CT to identify the availability of genetic educational materials and other resources available for families of infants and children with hearing loss and health care professionals. A sample of 100 pediatricians and pediatric audiologists were surveyed. The main objectives of the needs assessment was to 1) Identify what materials exist to educate families about a genetic evaluation for infants with hearing loss, 2) Define barriers that may prevent families from being informed the availability of genetic

services, 3) Identify resources needed to empower parents in the decision making process of their child's treatment and follow-up, 4) Identify resources needed to support policy change to include genetic testing as a standard of care in a post diagnostic evaluation.

The results of the surveys identified that the physicians had a general knowledge of the UNHS program and the expectations of the role of the PCP. All of the physicians indicated that they knew that all infants were screened for hearing loss at birth, and 95% reported that they confirm that the hearing screening was conducted, before discharge or at the initial well baby visit. Verification that the screening was conducted is a critical step in identifying infants who may have been discharged without a hearing screen, to assure that all infants are screened. There were clearly varying responses as to the likelihood of which type of specialist the provider would refer an infant to as part of the post diagnostic evaluation. Surprisingly, the less hours of genetic training that a provider reported having had, the more frequent the responses that they would 'very likely' make a genetic referral. The one consistent specialist that 87.5% of the pediatricians stated they would very likely or likely refer a child with a hearing loss to, is the otolaryngologist (ENT). This may be due the state legislation in place that requires an otolaryngology evaluation and medical clearance prior to hearing aides being dispensed. The overall varied responses indicated the need for provider education on the purpose of a specialty referral as part of the post hearing diagnostic evaluation, including when it is indicated.

The parent's educational level was identified as a factor that would somewhat or very much influence the pediatrician's discussion of genetic testing with the family in 52.5% of the responses. Although education level may not necessarily correspond with literacy level, it may affect the patient's understanding of the medical recommendation.

The needs assessment also supports the need for printed materials such as brochures or fact sheets, that could be distributed to families to supplement what was discussed by the provider. The pediatricians clearly expressed a need for printed educational materials (80% said nothing is available) and 70% stated that if materials were available, it would increase the likelihood of their discussion about genetics with the family. The materials will be developed be at an appropriate reading level for comprehension and will be tested using focus groups to assess family understanding.

Through this project DPH will develop informational and educational materials for families and health care providers on hearing screening, risk indicators, diagnostic and genetic evaluations and early intervention options and provide training to audiologists, PCP's and otolaryngologists.

Data Requirements

The UNHS program has an established internet-based reporting system by which birth hospitals report demographic and hearing screening data. The data is extracted daily into the Newborn Screening (NBS) tracking system, which is an Oracle database that is linked with the Newborn Laboratory Screening program, and the Birth Defect Registry. The NBS has extensive report capability that staff uses for tracking, follow-up and for state and federal reporting. In 2004 there were 42,543 live births in CT, of which 41,654 were screened for hearing loss before hospital discharge. There were 47 infants diagnosed with a hearing loss with the average age of diagnosis being 1.86 months. Nineteen infants for eligible for Birth-to-Three services and 16 were enrolled. The average age of enrollment into EI was 2.37 months of age. 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 NBS. 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 interdisciplinary family service plan (IFSP) written and it signed by a multidisciplinary team of professionals, including the PCP.

Identification of Target Population

Census data for 2002-2003 indicated that in Connecticut's population of about 3.4 million it included 2.6 million whites, 315,000 African American, 324,000 Hispanics, and 138,00 classified as other. While the total Connecticut population changed little since 1990, the proportion of minorities in the population has been increasing. Table 1 presents the proportion of the population by race and Hispanic ethnicity for six major cities in comparison to the State. While Connecticut population is almost 77% white, these cities have a much greater percentage of minority populations.

Table 1 Percent Population Distribution by Race and Ethnicity

	Connecticut	Bridgeport	Hartford	New Haven	New London	Waterbury
White Non-Hispanic	77	40.1	25.4	43.5	63.5	68.7
African American Non-Hispanic	9	26.6	37.2	37.2	17.7	13.7
Hispanic	10	30.2	35.5	15.8	15.2	16.2
Other	4	3.2	4.1	3.5	3.6	1.3

The 2000 U.S. census data reflects that 18.3% of Connecticut's population speaks a language other than English, with the Spanish being the predominant other language in 8.4% of the population.

Teen birth rates per 1,000 are highest for Hispanic women 84/1000, blacks are 51.4/1,000 and whites are 12.2/1,000. Pre-term births are highest in black women 13.6%, Hispanics are 11.1% and whites are 8.9%.

The distribution of wealth within Connecticut varies greatly by geographic area. The 2001-2003 median household income for CT was $55,004, higher than the national average of $43,527. The per capita income for the State had a wide range within the cities and towns. Hartford had the lowest PCI in the State, while New Canaan, a wealthy suburb near the New York border had a PCI of $91,777.

Poverty rates are defined as those who earn less than 100% of the Federal Poverty Level (FPL). The FPL threshold for a family of three was $14,128 in 2001 and $14,348 in 2002. Connecticut poverty rates indicate that 15% of the states children under 18 years of age live in families below the FPL, compared to national rates of 23%. Further analysis of the breakdown of poverty level by race identified 7% White, 28% Black, 32% Hispanic and 16% classified as other.

GOALS AND OBJECTIVES

Goal 1: To establish a continuous, formalized program to track infants lost to follow-up.

Objective 1: By December 1, 2005 a Health Program Assistant (HPA) will be hired to assist in tracking infants who were discharged without a hearing screen or who were identified as at risk for hearing loss from the initial screen and did not receive audiological follow-up. By March 1, 2006 a formalized Child Find program will be established. *Evaluation:* This goal will be evaluated using the UNHS data tracking system. Screening, diagnostic and lost-to-follow-up rates will be monitored. By September 1, 2006 the screening rates will increase to 99% and the lost to follow-up rates from screening will decrease to 10%. The lost to follow up from

diagnostics will decrease to 0.3%. **Goal 2**: To assure that all hearing impaired infants receive ongoing monitoring and are linked to a medical home to assure quality developmental outcomes. *Objective 2:* By March 1, 2006, DPH will contract with the three statewide early intervention audiology centers that specialize in working with infants and children who are deaf or hearing, impaired to provide ongoing monitoring and follow-up of infants with hearing loss who are not eligible for EI services. By July 1, 2006, 90% of families of infants with unilateral hearing loss or a bilateral hearing loss of <40db will be linked to a medical home, providers will be educated on developmental milestones, and families will be educated on environmental modifications that can facilitate hearing and speech development. The audiologists will provide a comprehensive audiological assessment at no charge to the family for those infants in which it is not a covered health insurance benefit. The assessments will include an OAE screening, tympanogram, acoustic reflex testing, ABR threshold measurement with frequency specific tone bursts, air and /or bone conduction ABR, speech discrimination assessment, visual reinforcement and play conditioning for the child 2 to 2 ½ years old. At the completion of this funding project the audiologists will prepare a report on the benefits of ongoing monitoring, family education and support. The information will be presented to the CT Birth-to-Three Advisory Board and they will be asked to reconsider eligibility guidelines for infants with hearing loss. *Evaluation:* This goal will be evaluated using the UNHS data tracking system. The reports of the ongoing evaluations will be reviewed and results entered into the UNHS tracking system. The numbers of infants who develop progressive loss and are referred to EI will be monitored. Successful achievement of this goal will be evidenced by the revision of the EI eligibility to include all infants with hearing loss. **Goal 3**: To have a mechanism in place to provide ongoing follow-up to infants who screen negative, but are identified as at risk for hearing loss. *Objective 3:* By July 1,

2006 UNHS staff will have a plan and protocols developed to implement a follow-up monitoring program for the children at risk for hearing loss. By July 1, 2006 the UNHS staff will collaborate with the CT Newborn Hearing Screening Task Force and will outline recommendations for follow-up monitoring of infants and children at risk. By October 1, 2006 DPH will increase awareness about risk indicators through education to hospital newborn screening staff in the 31 birth facilities. Hospital screening staff will be educated on the identification of risk indicators in newborns and the importance of educating families about the importance of ongoing monitoring of these at risk infants. The Department of Public Health will develop informational materials pertaining to audiological follow-up and monitoring for these infants and will disseminate the information to all health care providers by November 1, 2006. The nurse managers will be asked to assist in the development of the materials and/or to evaluate the materials before finalized to increase their involvement and awareness in the process. *Evaluation:* The UNHS tracking system will be used to evaluate this goal and objectives. The numbers of infants reported with risk factors reported through NBS will increase by 10% from 2004. **Goal 4**: Ensure that all birthing facilities with NICU's provide standardized newborn hearing screening prior to discharge. Objective 4: Provide funding to 4 NICU's to purchase ABR screening equipment so that all high- risk infants will have an ABR screening conducted prior to hospital discharge. By March 1, 2006, 100% of all NICU's will have ABR screening equipment available to screen high-risk infants. *Evaluation:* This will be evaluated using the UNHS tracking system to ascertain the first and/or second screening methods on NICU infants. By July 1, 2006 90% of all NICU infants will have an ABR screening before discharge. This project addresses the Healthy People 2010 objective of assuring that children with special health care needs and their families have access to appropriate, adequate and timely services that are family-centered,

comprehensive, coordinated and culturally competent. **Goal 5**: To provide informational and educational materials for families and health care providers on hearing screening, risk indicators, diagnostic and genetic evaluations and early intervention options. Objective 5: By December 1, 2005 a pamphlet will be developed for families with information on the availability of genetic testing in hearing loss. By June 30, 2006 a resource guide will be developed to educate health care providers on all aspects of the UNHS program, and support services available for families of infants with hearing loss. By June 30, 2006 an educational newborn hearing conference will be held for audiologists, otolaryngologists and PCP's to inform them about all aspects of the UNHS program and to educate them on the advances in medical genetics and hearing loss. *Evaluation:* A pre and post-test will be given to evaluate provider knowledge gained through the conference. At least 90% of the Diagnostic Testing Centers will have participated in the educational conference.

PROJECT METHODOLOGY

Goal 1: The DPH will establish a continuous, formalized program to track infants lost to follow-up. This project will support the salary of one fulltime Health Program Assistant who will be hired by December 1, 2005 to assist in tracking infants who were discharged without a hearing screen, who were identified as at risk for hearing loss from the initial screen and did not receive audiological follow-up, or who did not pass the hearing screen and did not receive diagnostic testing. By March 1, 2006 a formalized child find program will be established The UNHS database will be used to generate tracking reports of infants who did not have the initial hearing screen and/or did not pass the hearing screen and have not received audiological follow-up testing. Letters will be sent to the child's primary care provider and responsible party, informing

them of the need for screening, diagnostics and/or follow-up testing. Telephone contact will be attempted for families that do not respond to the mailing of letters. UNHS staff will utilize the CT Immunization Registry Tracking System to identify and locate infants who cannot be located due to name or address changes.

Goal 2: DPH will assure that all hearing impaired infants receive ongoing monitoring and are linked to a medical home to assure quality developmental outcomes. Connecticut has three early intervention specialty centers that provide audiological services, family education, support and advocacy for infants and children with hearing loss. Through this project the DPH will contract with the specialty providers for a three-year period to provide a hearing assessment every six months to children with hearing loss who are not eligible for EI services. The types of hearing loss included in this objective may be a unilateral hearing loss of any degree or a bilateral loss that is mild in one ear, and mild to profound in the other ear. The cost of each assessment will be $150 per child and will include a comprehensive audiological evaluation, family education as to methods to enhance hearing through environmental accommodations, family support, and coordination of care and services through the child's medical home. Infants identified and diagnosed with a progressive hearing loss that is bilateral, and 40dB or greater, will be referred to Early Intervention for an eligibility determination. The audiologists will send reports of the diagnostic evaluation to the UNHS program for tracking and monitoring and will send the results of their evaluation and recommendations to the child's PCP. Through this method Connecticut will assure that these children with special health care needs are linked to a medical home, and that the health care provider and audiologist provide coordinated services to assure that each child reaches his maximum potential and that avoidable speech and language delays are averted.

Goal 3: DPH will establish a mechanism to provide ongoing follow-up to infants who screen negative, but are identified as at risk for hearing loss. The UNHS program will enlist the support of the expertise available through the CT Newborn Hearing Screening Task Force members and will outline risk indicators and the recommendations for follow-up monitoring of infants and children at risk. The DPH will develop informational materials pertaining to audiological follow-up and monitoring for these infants and will disseminate the information to all health care providers, audiologists and birth hospital NBS staff. The hospital nurse managers will be invited to review the materials during the development stages. The information will also be made available on the DPH UNHS website. An annual meeting will be held with the 31 birth hospital Newborn Screening staff to educate them on the risk indicators, the follow-up process and other aspects of the UNHS program.

Goal 4: DPH will ensure that all birthing facilities provide standardized newborn hearing screening prior to discharge. This project will support funding for four (4) hospital NICU's to acquire automatic brainstem response (ABR) screening equipment. This will assure that the ABR screening equipment is available and accessible to the NBS screening staff of these high-risk infants. The DPH will develop a Personal Service Agreement (PSA) with each facility to purchase the equipment. An estimate of $7,900, including screener and printer was obtained for the purpose of budget planning for this project. The PSA will state that the facility will purchase an ABR screener/printer for use with the NICU population, and will submit the receipt to the DPH. The DPH will reimburse the facility for an amount up to $7,900. It is expected that by March 1, 2006, 100% of all of the CT NICU's will have ABR screening equipment available to screen high-risk infants before discharge.

Goal 5: The DPH will develop informational and educational materials for families and health care providers on hearing screening, risk indicators, diagnostic and genetic evaluations and early intervention options. A pamphlet will be developed for families to inform them that not all hearing loss occurs at birth, and that certain indicators warrant ongoing audiological assessments. It will stress the importance of ongoing follow-up and monitoring for children with risk indicators. The risk indicators identified in the pamphlet will be those outlined by the Joint Committee on Infant Hearing (JCIH).

A brochure will be developed to educate families on genetic testing in hearing loss. It will explain the risks and benefits of genetic testing to help empower parents in the decision-making process for their child. The brochure will be at an appropriate reading level (grade 4) and will be available in English and Spanish. The information in the brochure will be piloted with families through a focus group to assess the level of understanding and to make modifications as necessary. The brochures will be distributed to licensed audiologists in the state, primary care providers and will be accessible on the DPH UNHS web site.

A resource guide will be developed to educate health care providers on all aspects of the UNHS program including: screening, diagnostic evaluation, referrals to specialty providers and early intervention options and support services available for families of infants with hearing loss. The resource guide will be distributed to PCP's, audiologists and otolaryngologists and will be available on the DPH UNHS web site.

A Newborn Hearing Symposium will be held for audiologists, otolaryngologists, primary care providers and other specialty providers. The event will bring together the members involved in the child's medical home to support the integration of services, care coordination, screening, diagnosis, early intervention and the follow-up and management of infants with hearing loss.

COLLABORATION AND COORDINATION

The UNHS program has demonstrated the ability to work with a broad range of consumer and professional groups. Internally the UNHS program is one component of the Newborn Screening program, which includes the Laboratory Newborn Screening program. Additionally, the DPH UNHS program manager has worked collaboratively with the State Department of Information Technology (DoIT) on developing the internet-based reporting system for hospitals to report hearing, lab screening results and birth defect data to DPH in a real time, secure manner. DoIT staff serves as a liaison to the Newborn Screening staff in the electronic transfer of data from the birth hospitals to the CHP data management system. Nursery staff in the hospitals has access to a telephone "Help Desk" which is staffed with DPH personnel. The "Help Desk" enables hospital staff the opportunity to get technical assistance on the electronic reporting of newborn screening information to the DPH.

Through annual conferences and ongoing onsite visits to all birthing facilities in the state, the UNHS program manager has established strong working relationships with the 31 hospital nurse managers who oversee the hospital screening programs. The nurse managers communicate with the UNHS program manager frequently by telephone and/or e-mail with any questions pertaining to newborn hearing screening and are prompt to reply with tracking inquiries.

The DPH UNHS program manager is a member of the CT Newborn Hearing Screening Task Force. The group meets monthly and is comprised hospital nurses, audiologists, early intervention staff, a Commission on Deaf & Hearing Impaired social worker, a neonatologist and family/consumers. The Task Force identified the recommended standards for the battery of tests that are needed to conduct audiological diagnostic testing of infants, which was distributed to all audiologists, birth hospitals, pediatricians and family practitioners in the state. The Task Force

members collaborate with the DPH in the annual conferences with the diagnostic audiology centers and birth hospitals to educate them on the UNHS program guidelines, reporting requirements, time frames for testing and the referral process to Birth-to-Three and the CSHCN program, and other relevant aspects of newborn screening. The CT Newborn Hearing Screening Task Force's enthusiasm and commitment to UNHS has been a vital force in the success of the program and is evidenced by their letter of support (see Appendix I, Letter of Support).

CT UNHS staff has participated in the annual MCHB/CDC UNHS Conferences since the inception of the state's UNHS program and was a member of the conference planning committee in 2004-2005. In 2004, CT served as a pilot state to test the Department of Health and Human Services Health Resources and Services Administration new online UNHS grant application.

In 2004 CT was selected to participate in the National Center for Hearing Assessment and Management's "Hearing Head Start Project". The project was designed to provide selected Early Head Start Programs with screening equipment and the training and tools necessary to monitor, refer and report on the children's hearing status. CT created a team of trainers comprised of two audiologists, one early intervention teacher for the deaf, and one neonatal intensive care nurse. The CT Team conducted a one-day training for Early Head Start (EHS) personnel from five centers across the state. The UNHS Program Manager coordinated the in-state project and training. The training was very well received by the EHS staff, and the project is ongoing.

CT has long been an active member of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA). The CT UNHS Coordinator served as the DSHPSHWA President-Elect from 2003-2004, as President from 2004-2005 and will serve as Past-President in 2005-2006.

The UNHS Program Manager is an active member of the Connecticut Genetics Advisory Committee. The group meets quarterly to discuss expansion of screening and issues relevant to Newborn Screening and Genetics.

The Newborn Screening staff meets monthly with the State Laboratory Clinical Supervisors and Quality Assurance staff to address issues specific to Newborn Screening and the electronic transmission of data from the birth hospitals.

The DPH employs a part-time CSHCN Family Advocate. The Family Advocate will provide support to the five new Regional medical Home Centers. UNHS staff has utilized the Family Advocate to review educational materials for families through focus groups. This assures that the UNHS program materials are family friendly, culturally and linguistically appropriate and enables parents an opportunity to participate in the development of State educational resources. The Family advocate will review the family educational materials outlined in this project and will pilot the materials through focus groups with families.

DPH collaborates extensively with the DMR, Birth-to-Three System which is the lead agency for the Individuals with Disabilities Education Act (IDEA), Part C. Presently, all infants with a bilateral hearing loss of 40 dB or greater are referred by the diagnosing audiologist to the Birth-to-Three Referral Line and are automatically eligible for services. The UNHS Program Manager confirms an infant's enrollment (including date of referral and center of enrollment) into the Birth-to-Three System by telephone with the Birth-to-Three Director. This assures that the DPH is able to track infants from the screening process, through the attainment of early intervention services.

The DPH and Birth-to-Three developed an informational newborn hearing screening brochure for parents (at a grade 4 reading level), which is available in English and Spanish. The

brochures identify normal speech and hearing development, explain the different types of hearing screening available, and answers commonly asked questions. The brochures have been distributed to hospitals throughout the state and are given to all patients giving birth. DPH recently revised the brochure to include a statement that informs parents that hearing screen results are forwarded to the DPH for tracking and follow-up.

The DPH works collaboratively with the American Academy of Pediatrics (AAP) CT Chapter to disseminate information to the health care providers about the benefits of UNHS and the CT UNHS program. The CT Chapter Champion of the AAP has been a longstanding member of the CT Newborn Screening Task Force.

The CT Chapter of Self Help Group for Hard of Hearing People (SHHH) worked collaboratively with the DPH to develop a brochure for families outlining the resources available in the state for children that are deaf or hearing impaired. The SHH North East Chapter created a resource library for their community.

The UNHS Program Manager is an active member of the Commission on Deaf and Hearing Impaired Advisory Board (CDHI), which meets quarterly. The Commission has a strong commitment to UNHS and is currently working with the Department of Children and Family Services (DCF) to increase the availability of foster care to children that are deaf or hearing impaired. The CDHI provides sign language interpreters for deaf parents as needed.

An UNHS video for health care providers was produced with funding by the CT Perinatal Association. DPH purchased and distributed the videos to all birthing facilities to use for staff development and training and utilized this video as part of the training for health care professionals.

The DPH participates in Birth-to-Three Interagency Coordinating Council (ICC) whose governor appointed membership includes: parents of children who are enrolled in the Birth-to-Three system, members of the General Assembly, a trainer of early intervention personnel, a member of AAP, State agency representatives, and approved providers of early intervention services. The group meets quarterly to discuss coordination of children's activities between Birth-to-Three and other State agencies.

ADMINISTRATION AND ORGANIZATION

The DPH is the lead agency for public health initiatives in the state. The Bureau of Community Health (BCH) is one of six bureaus within the DPH. The UNHS program, as described in the state's MCHB Block Grant application, is located in the BCH, Family Health Division (FHD). Other programs in the FHD include the Genetics/Newborn Laboratory Screening program, Sickle Cell services, Sickle Cell Transition project, the Title V Children with Special Health Care Needs Program, the Birth Defect Registry and School Based Health Centers. The UNHS Program is housed in the School and Adolescent health Unit (see Appendix G, Organizational Chart). Donna C. Maselli, RN, BS, will serve as the UNHS Project Manager.

ORGANIZATION EXPERIENCE, CAPACITY AND AVAILABLE RESOURCES

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

The Department of Public Health, Bureau of Community Health, is home to the state Title V program for Connecticut (CT).

The UNHS program has the support of the Commissioner DPH in creating an integrated Child Health Information Profile. In 2004, as a result of widespread interest among program,

managerial, and executive staff at the DPH, a draft Data Integration Plan was generated which identified fourteen (14) existing health-related databases within DPH containing information mandated by Connecticut General Statutes (CGS) and controlled by Regulations of Connecticut State Agencies.

As a result of the Data Integration Plan, J. Robert Galvin, MD, MPH, Commissioner of the DPH, set goals for improved and enhanced communications between and across programs that reduces barriers to effectiveness and increases efficiency. To further address these goals, the Commissioner formed a Virtual Child Health Bureau (VCHB). The VCHB is comprised of an interdepartmental group of database users and managers. Consistent with the objectives of the Data Integration Plan described above, the DPH Virtual Child Health Bureau, now seeks to enhance Connecticut's public health infrastructure with the creation of an integrated and comprehensive electronic data system that combines child health data within DPH, called Health Information Profile (HIP) Kids or HIP-Kids.

Of the fourteen mandated health-related databases within DPH, eleven databases contain unique identifiers that can be matched and contain data that would contribute uniquely to HIP-Kids. The database that is a natural first focus of HIP-Kids is the Child Health Profile (CHP), which includes Newborn Laboratory Screening Program, Birth Defects Registry, Newborn Hearing Screening Program and the Electronic Vital Records System (EVRS).

Essential public health functions will also be enhanced with the development of HIP-Kids through: 1) better coordination of medical services to all children, and especially children with special health care needs, through linkages with qualified medical home environments; 2) reduced health disparities among childhood disease prevention activities through better outreach to the "hard to reach" populations; and 3) reduced need to disclose confidential information that

is now needed to generate local database linkages. Enhanced assessment activities should include: 1) an increased ability to evaluate population-based health activities; 2) improved data quality through better data validation and coordinated data improvement efforts; 3) enhanced comprehensive data accessibility to support grant activities, health programming, and to support data requests from sources outside DPH; and 4) enhanced analyzing, interpreting, monitoring, and reporting activities by DPH staff.

The Child Health Profile collects it's data through an internet-based reporting system by which the birth hospitals report to the Newborn Laboratory Bloodspot program, the UNHS program and the Birth Defect Registry. The electronic reporting system is called the Newborn Screening System (NSS). In 2002 when electronic reporting through the NSS was implemented, the system linked only the UNHS and Newborn Laboratory Screening program data. In January 2004 the Birth Defect Registry was linked to the NSS.

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. This is a unique identifier that is used for tracking infants in the UNHS program, Newborn Laboratory Screening program, the Birth Defect Registry and at the State Laboratory where the bloodspot specimen is tested. The newborn's electronic record is comprised of four data panels. The first is the biographical panel, which is shared between all three programs and the State Lab (see Appendix A, Hospital Reporting Screens). 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 Screening panel, which collects heelstick specimen collection information, transfusion information and the status of the newborn. The third panel is the UNHS 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 completed for each individual panel, the record is electronically transmitted to a server at the DPH. The encrypted data is transmitted via a virtual private network, where the record and information specific to that program is then available for extract by DPH program staff. A unique feature of the NSS is that the hospitals have the ability to electronically transfer the NSS 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 and imported into the UNHS tracking system daily.

UNHS program staff has the ability to generate tracking and surveillance reports, as well as statistical reports by hospital, of the number of infants screened, results of the first and second screens, number not tested, deceased, refused, referred, diagnosed and lost to follow-up (see Appendix E, UNHS Annual Data Report).

The monthly UNHS tracking reports that identify infants of whom hearing screening results were not received are sent to the birth hospitals. The hospitals return the data to the UNHS program indicating the date, method and results of the hearing screen, or whether the infant was missed, refused, transferred or expired. The data is then entered into the UNHS tracking system. In 2004 CT received electronic screening data on 41,739 infants.

CT has 18 designated state Diagnostic Testing Centers that submit audiological testing results to the DPH on a standardized reporting form (see Appendix F, Audiology Reporting Form). Information collected 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. Enrollment into the Birth-to-Three System, CT's early intervention program, is confirmed for each individual case and the date of referral, date of eligibility and center of enrollment is identified.

All infants identified with a hearing loss through UMHS are referred at the time of diagnosis to early intervention. The State Department of Mental Retardation is the lead agency for Connecticut's Individual's with Disabilities Education Act (IDEA) Part C, early intervention program (CT Birth to Three). Birth-to-Three has three specialty centers that specialize in providing services for children who are deaf or hearing impaired, American School for the Deaf, CREC/Soundbridge and the New England Center for Hearing Assessment and Management. Birth-to-Three staff developed a *Service Guideline for Families of Infants that are Deaf or Hearing Impaired* that is distributed to families upon referral. UNHS staff confirms via telephone the infant's date of referral and date and center of enrollment with the Birth-to-Three Director. The UNHS staff provides Birth-to-Three staff with the date of diagnosis, type and degree of hearing loss. The information is added to the UNHS tracking system. The Birth-to-Three specialty centers report to DPH the date of fitting for amplification on infants after parental consent is obtained.

Appendices