Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening Project

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PROBLEM: Infants who do not pass newborn hearing screening do not consistently receive follow-up testing and may be at risk for speech, language, social, and other delays. The Connecticut Department of Public Health, Early Hearing Detection & Intervention Program has initiated a project to reduce the loss to follow-up/loss to documentation of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery by utilizing specific, targeted and measurable interventions. This project will use quality improvement methodology to achieve measurable improvement in the number of infants who receive documented, appropriate, and timely audiological testing and intervention services in order to assure better developmental outcomes for infants identified with hearing loss. The CT DPH will build upon the well-established and state-mandated EHDI Program to ensure: that newborns are screened for hearing loss by 1 month of age; that timely audiological follow-up is provided for those infants for whom further assessment is indicated by 3 months of age; and that infants diagnosed with a hearing loss are enrolled in an early intervention program by 6 months of age.

PROJECT GOAL/AIM: To obtain at least a 5% per year reduction in LTF/D in each of the three grant years. By August 31, 2017, CT EHDI will use quality improvement methodology so that LTF/D of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery as reported through the CDC annual EHDI survey declines from a state average of 35% (2012 annual data) to a state average of 20% (2015 annual data).

METHODOLOGY: The project aim will be met through several methods: (1) quality improvement methodology (Plan, Do, Study, Act Cycles); (2) tracking and surveillance; (3) provider and parent education – including on-site education and printed resources; and (4) partnership building. To achieve this reduction, a series of aims, utilizing the Plan-Do-Study-Act model for improvement, shall be implemented by 8/31/17. Aim 1: Each of the 29 CT birth facilities and one licensed midwife practice will demonstrate individual hearing screening rates equal to or greater than 99% and a referral rate of less than 4% of the total infants screened by their facility. Aim 2: Eighty percent of infants who do not pass their hearing screening will receive an audiological evaluation by 3 months of age (90 days) and the results of this evaluation will be shared with the State EHDI Program. Aim 3: Ninety-five percent of infants with identified hearing loss will be referred to Birth to Three. Aim 4: Eighty-five percent of infants will be enrolled in EI by 6 months of age and their date of entry will be shared with the State EHDI Program.

COORDINATION: The EHDI Program will collaborate with the following stakeholders to accomplish the project aims: birth facilities; nurse midwives; audiologists; otolaryngologists; primary care providers; CYSHCN Program – Medical Home Initiative networks; Childhood Immunizations; the Home Visiting Program; IDEA Part C EI services - CT Birth to Three, including 3 hearing specialty programs; technology partners - CT DAS Bureau of Enterprise Systems and Technology and hired contractor, Consilience; and the CT EHDI Task Force (advisory committee) and Quality Improvement Team.

EVALUATION: The project will be evaluated via ongoing internal reviews of screening, referral, diagnosis, and early intervention statistics and LTF/D rates as well as monitoring and tracking individual hospital performance measures. The specific strategies and measures proposed will be evaluated in large part based on data available through the statewide EHDI information system, which falls within CT DPH's Maven: Newborn Screening System. Proposed educational initiatives will include participant evaluation components.

ANNOTATION: CT will build on the established EHDI Program to reduce the number of infants lost to follow-up after failure to pass newborn hearing screening in an effort to improve quality developmental outcomes for infants identified with hearing loss. This project aims to ensure all infants are screened for hearing loss before hospital discharge and that home births are screened; that clear communication about the need for follow-up exists between pediatric health care providers and families; that timely follow-up is provided when indicated; that eligible infants are enrolled in an EI program by 6 months of age; and all identified infants are linked to a medical home. Educational opportunities will be facilitated for health care providers and families on various aspects of the EHDI process.

INTRODUCTION

The Connecticut Department of Public Health, Early Hearing Detection & Intervention (EHDI) Program has initiated a project to reduce the loss to follow-up/loss to documentation of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery by utilizing specific, targeted and measurable interventions. This project, called *Reducing loss to Follow-up after Failure to Pass Newborn Hearing Screening*, will use quality improvement methodology to achieve measurable improvement in the number of infants who receive documented, appropriate, and timely audiological testing and intervention services in order to assure better developmental outcomes for infants identified with hearing loss (HL).

Connecticut (CT) defines infants who are lost to follow-up/lost to documentation (LTF/D) as those who refer (or fail) their newborn hearing screening at birth and have not had a completed audiological hearing evaluation submitted to the Connecticut Department of Public Health (CT DPH) by 12 months of age. This definition excludes expired infants, those infants whose responsible party refused follow-up testing, and infants who live or move out-of-state.

Infants who do not pass their hearing screening at birth sometimes receive inconsistent follow-up testing and, as a result, may be at risk for speech, language, social, and other delays. Connecticut's overarching project goal (aim) is to obtain at least a 5% per year reduction in LTF/D in each of the three grant years. By August 31, 2017, CT EHDI will use quality improvement methodology so that LTF/D of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery as reported through the CDC annual EHDI survey declines from a state average of 35% (2012 annual data) to a state average of 20% (2015 annual data). To achieve this reduction, a series of aims, utilizing the Plan-Do-Study-Act (PDSA) model for improvement, shall be implemented. The CT DPH will build upon the well-established and state-mandated EHDI Program to meet the aims identified in this proposal by August 31, 2017. The aims are as follows:

- Aim 1: Each of the 29 CT birth facilities and one licensed midwife practice will demonstrate individual hearing screening rates equal to or greater than 99% and a referral rate of less than 4% of the total infants screened by their facility.
- Aim 2: Eighty percent of infants who do not pass their hearing screening will receive an audiological evaluation by 3 months of age (90 days) and the results of this evaluation will be shared with the State EHDI Program.
- Aim 3: Ninety-five percent of infants with identified hearing loss will be referred to Birth to Three.
- Aim 4: Eighty-five percent of infants will be enrolled in EI by 6 months of age and their date of entry will be shared with the State EHDI Program.

The project will be evaluated via ongoing internal reviews of screening, referral, diagnosis, and early intervention statistics and lost to follow-up rates as well as monitoring and tracking individual hospital performance measures. The specific strategies and measures proposed will be evaluated in large part based on data available through the statewide EHDI information system, which falls within CT DPH's Maven: Newborn Screening System.

Since 2002, CT has had a uniform state registry that incorporates standardized methodology, reporting and system evaluation. Between 2008 and 2011, CT developed the Maven: Newborn Screening System (Maven: NSS), an integrated web-enabled, electronic messaging capable, secure surveillance system. The Maven: NSS went into production for birth facility reporting at the beginning of 2012. As with the former Newborn Screening System, birth facilities report real-time newborn biographical and demographic information, and newborn blood spot screening, hearing screening, and birth defect data to the DPH via the Maven: NSS. An automatic de-duplication algorithm is built in to the Maven: NSS application in order to alert data entry users of possible repetition. The DPH Maven project has enhanced the EHDI Program's tracking and surveillance capabilities to: 1) allow for accurate reporting on the status of every occurrent birth throughout the EHDI process as well as 2) evaluate progress toward national EHDI goals via a number of customized reports. Also, staff can automatically generate tracking letters in the Maven: NSS, which are sent to families and primary care providers of infants without documented follow-up at 7 weeks of age. The system was developed by Consilience Software, Inc., and the EHDI Program is charged for custom report requests that require additional system developer's time outside of the vendor maintenance agreement.

The CT EHDI Program will collaborate with various EHDI stakeholders and early childhood programs to meet programmatic and national "1-3-6" goals – all infants have their hearing screened before one month of age; for those infants who fail to pass newborn hearing screening, audiologic diagnosis is completed before three months of age; and infants with a confirmed hearing loss enter into a program of early intervention before six months of age in order to facilitate age appropriate development of language and social skills. Connecticut participated in the National Initiative for Children's Healthcare Quality (NICHQ) Improving Hearing Screening and Intervention Systems (IHSIS) Learning Collaborative, from June 2012 to September 2013. As a means for continuing the IHSIS state team's work, the CT EHDI Task Force (essentially an advisory committee) now includes Quality Improvement as a standing agenda item at its monthly meetings. Activities that have been proven effective in ensuring appropriate follow-up will be included in the work plan in combination with new strategies/changes. CT EHDI's quality improvement team will use PDSA cycles to test changes on a small scale, quickly identify promising ideas, and expand changes that show promise in order to test on a larger and larger scale, until the team is confident that the change should be adopted system-wide. Furthermore, Massachusetts has invited CT and other New England states, as well as New York, to participate in quarterly conference calls to collaborate and share quality improvement work taking place throughout the region. Additionally, contracts will be maintained to facilitate educational opportunities for health care providers and families on various aspects of the EHDI process, using funds from this proposal.

NEEDS ASSESSMENT

A comprehensive EHDI infrastructure is in place in CT. Connecticut's greatest resource is the legislation that has been in place since 1999, which mandates all birth hospitals 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 (CT General Statute 19a-59-1). There are 29 birthing facilities and one large midwife practice in the state (<500 births: 8 facilities / 500-1,000 births: 5 facilities / 1,000-2,000 births: 10 facilities / 2,000-2,500 births: 4 facilities / > 2,500: 3 facilities).

Screening

Since the universal newborn hearing screening program was implemented in CT in 2000, screening rates have consistently improved and have been 99% or better for the past eight years. All hospitals utilize a two-step screening program. Infants receive the first hearing screen using either Otoacoustic Emissions (OAE) or Automated Auditory Brainstem Response (AABR) screening equipment. Infants that do not pass the first screening have a repeat screening before discharge using the AABR method. As of 1/1/07, CT required all NICU babies to have an AABR screening to identify infants that may have auditory neuropathy/dys-synchrony. All newborn hearing screening data is electronically reported by the birth facility to the DPH. 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 OAE screening equipment. The midwives use the portable screening equipment to screen home births for hearing loss within one week of birth, and they electronically report newborn screening data to DPH through the Maven: NSS.

According to CT Vital Records data there were 37,294 live births in CT in 2012, of which 36,906 (99%) have documented hearing screening results, 0.38% (140) died prior to screening, 0.07% (27) of parents refused the screening, and the remaining group of babies have no hearing screening on record. Of those babies screened, 98.7 percent were screened before 1 month of age. CT's EHDI Program staff use the Maven: NSS to identify individual birth facilities that do not monitor their incomplete hearing screening results workflows on a monthly basis. A workflow is a system-generated running "to-do" list available to hospital users for quality assurance purposes. There are two hearing screening workflows in the Maven: NSS that identify babies missing hearing screening data:
1) *Cases with Incomplete Hearing Screening Information* – This workflow identifies babies for whom additional hearing screening information is required, such as the screening date, screener's last name/first name, screening method, right and left ear results, and when a baby does not pass the first screening, the system looks for a second screening; and
2) *Missing Hearing Screening Results* – This identifies babies for whom additional hearing screening right and/or left ear results need to be entered as well as babies who were entered as missed (screening not performed).
Babies who are missing hearing screening information in the system and are under the care of an individual birth facility, including a transfer hospital, will appear on that facility's workflows from the moment that record is created (hospitals typically create a newborn screening record for a baby on the day of birth). Once a user enters the required information for a baby in the system, that baby will no longer be included in the hearing screening results workflows. Based on a

statewide analysis, 18 of CT's 30 birth facilities monitor their hearing screening workflows on a weekly to monthly basis.

A data sharing agreement has been in place between the DPH Family Health Section/Newborn Screening Programs and the DPH Vital Records Program since 2010. A two-way, automated matching process between the electronic vitals records system (EVRS) and the Maven: NSS was fully tested over the course of a year and implemented in production in June 2013. EVRS records from 2011 – 2013 were matched and imported into the Maven: NSS on a rolling basis, subsequently providing missing demographic information and facilitating tracking and surveillance activities to accurately report the screening status of all occurrent births. Now that Maven is in production and matching functionality is in place and being regularly monitored, the 2012 total birth count was the closest it has ever been to the EVRS Occurrent Birth count. Regardless, the reason for the discrepancy (41 records) is being examined to further improve reporting accuracy. Also, there are now query mechanisms in place to identify those occurrent births that had a birth certificate created, but were not matched to an NSS case or vice versa, NSS records without an EVRS match. Now that identifiable data on unmatched records is available, DPH staff can ascertain who these babies are, why they may be missing from either database, or whether the infants were screened. It has been determined that many of the unmatched records are a result of out of hospital births or live births that died shortly after delivery and were never entered in the NSS.

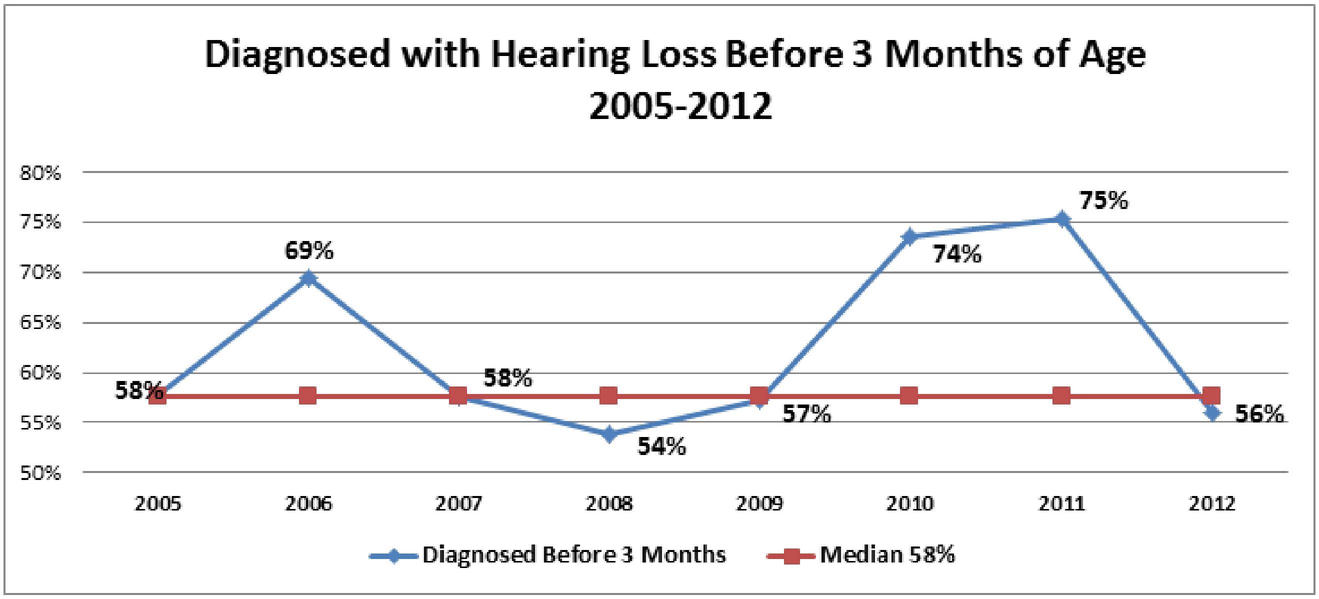
Diagnosis

Infants who do not pass a second hearing screening prior to discharge from a CT birth facility are referred to one of the seven 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, have experience working with infants and children, and conduct the test battery recommended by the CT EHDI Task Force for the diagnostic hearing testing of infants who do not pass the hearing screening conducted at birth. Three hospital-based audiology centers conduct the majority of infant diagnostic testing; CT Children's Medical Center, which includes two satellite locations, Yale New Haven Hospital, and Lawrence & Memorial Hospital. Although CT is a relatively small state, transportation issues present barriers for families without their own vehicle and the western portion of the state has a particularly high need for additional audiological services. Infant diagnostic testing centers submit individual and identifiable audiological testing results to the EHDI Program on a standardized paper reporting form via fax, and EHDI staff manually enter the diagnostic information into the program database.

In 2012, a total of 579 infants did not pass a hearing screening prior to discharge (1.55% of total births). 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. Hospitals are encouraged to complete the two-stage hearing screening at birth and 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).

However, about one-third of CT birth facilities conduct outpatient hearing rescreens. This protocol is acceptable provided referral rates remain under 4%.

In 2012, 309 infants were documented to have diagnostic testing revealing hearing within normal limits, and of those babies: 280 (91%) had follow-up before three months of age. Fifty infants were documented to have a diagnosis of congenital hearing loss, and of those babies: 28 (56%) were diagnosed before 3 months of age, 11 (22%) were diagnosed between 3 and 6 months, and 11 (22%) were diagnosed after 6 months of age. The graph below reflects an improving trend in age at diagnosis of hearing loss in 2010 and 2011, but a return to the median in 2012. EHDI staff continue to monitor trend data to identify areas for improvement.



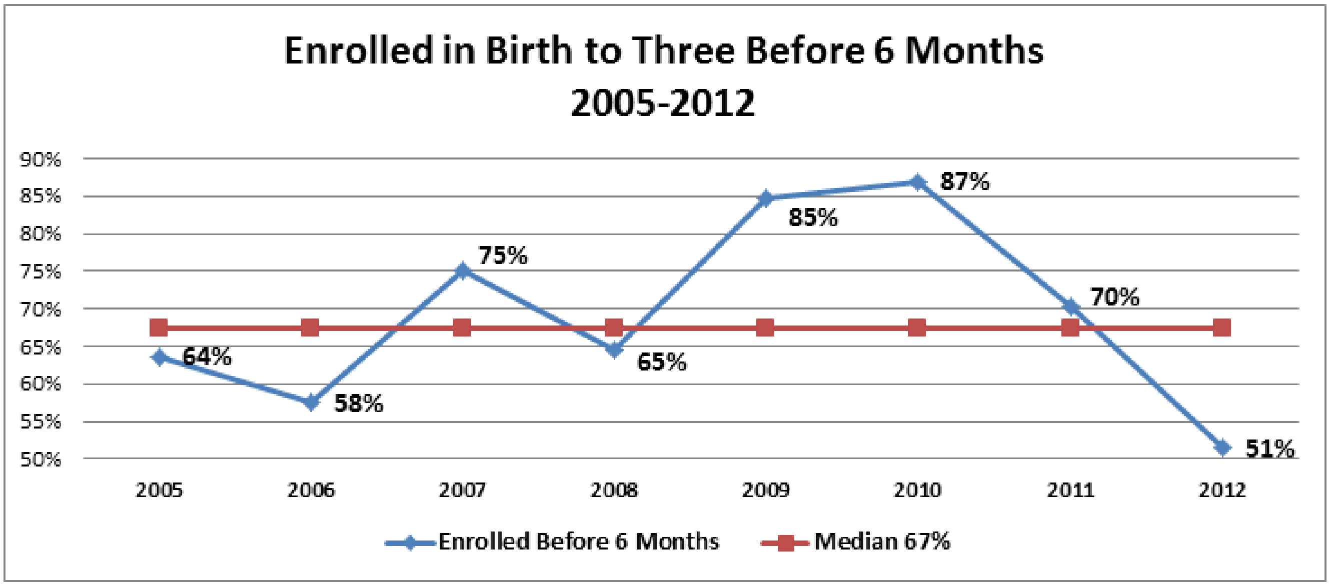
Connecticut's 2012 hearing loss ratio (50 / 37,294 = 0.134%), falls below the national statistic 2-3 babies per 1,000 births (0.2 - 0.3%), but still within the state's typical rate of identified hearing loss.

Early Intervention

Connecticut 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. Connecticut 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). The CDI caseworkers assess the caller's situation and make referrals to: the CT Birth to Three System, Ages & Stages, Preschool Special Education, and/or the Medical Home Initiative for Children and Youth with Special Healthcare Needs (CYSHCN). All infants identified with a hearing loss should be 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, Capitol Region Education Council (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. Families pay for Birth to Three services based on a sliding-fee scale.

The DPH has had a Memorandum of Agreement (MOA) with the CT Department of Developmental Services (DDS), the lead agency for Part C of IDEA (Individual with Disabilities Education Act), since 1999 (last revised 7/2012) to share program data on infants identified through EHDI. This MOA allows the two agencies to collaborate on the early identification and habilitative treatment of infants with hearing impairments by permitting the exchange of data between DDS and DPH. This collaboration ensures that infants with diagnosed hearing loss are enrolled in the Birth to Three System.

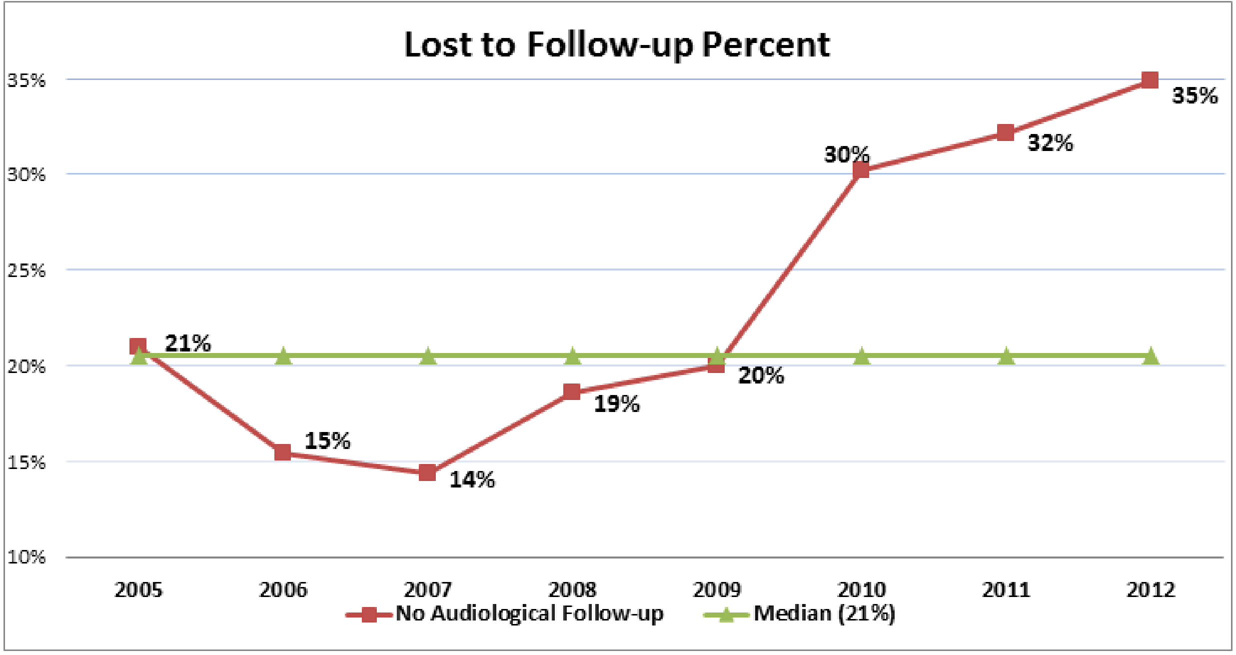
In 2012, 84% (42) of those infants identified with hearing loss were referred to Birth to Three. Thirty-five of these infants have been deemed eligible for EI and subsequently enrolled. There is no documentation of a referral to Birth to Three for eight infants who may or may not have been found eligible for EI services. Fifty-one percent of the 35 children referred for EI services were referred before 6 months of age, which falls below the median percentage over the last eight years, as seen in the graph below.



Staff from the EHDI program will continue to monitor Birth to Three enrollment trend data in subsequent years in order to identify what may explain the 2012 decline.

Infants with No Documented Follow-up or Follow-up is In Progress

In 2012 35% (204) of infants who did not pass newborn hearing screening did not have a completed diagnosis. CT has seen its loss to follow-up rates fluctuate widely over the last eight years as seen in the graph below, which suggests a problem with documented follow-up rather than true lack of follow-up.



Furthermore, in previous years (2005-2009), EHDI staff conducted extensive tracking efforts beginning with letters sent to the child’s responsible party and primary care provider (PCP) 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. If no response was received within a month, follow-up calls were placed to the PCP and/or parent. Personnel changes, including a reduction in overall staff hours dedicated to tracking and follow-up activities aimed at reducing loss to follow-up, likely contributed to poorer follow-up data during 2010-2012.

The CT EHDI Program is currently staffed at 2.1 FTE, which includes the two part-time staff identified in the attached budget narrative and a full-time CDC funded Newborn Hearing Screening Tracking and Systems Enhancement Liaison. Since hiring this additional 1.0 FTE staff person in May 2012, and receiving formal training in the PDSA model of improvement through participation in the IHSIS Learning Collaborative, EHDI staff have re-visited tracking letters as a promising strategy for reducing LTF/D and have approached it using quality improvement methodology. The PDSA is as follows:

Plan: In order to more accurately determine the follow-up status of babies who fail the newborn hearing screening, EHDI staff planned to send tracking letters to both the mother/parent of babies who did not pass newborn hearing screening and copy the PCP of record. If no response

was received within a month's time, EHDI staff planned to initiate a phone call to the PCP's office. The predicted result is more accurate documentation of follow-up and an increase in the number of babies with a complete diagnostic evaluation reported to the state EHDI program. This strategy has been through several iterations / adaptations as described below.
Do: In September 2013, a workflow identifying children born between July 1, 2013 and July 15, 2013, who did not pass the newborn hearing screening at birth and for whom there was no documented follow-up (at 6-8 weeks post-screening) was reviewed to determine the recipients of tracking letters. Tracking letters were system generated for the selected group and mailed to the parent and PCP on the same day. The parent letter included the brochure: *A Parent's Guide to Diagnostic Hearing Testing of Infants,* which includes a list of infant diagnostic testing centers. The PCP letter included the same list of audiology centers and a fax-back-form asking the provider to submit an update on the child's follow-up status, as well as giving the option of indicating whether or not the baby is seen at their practice.
Study: Ten letters were sent as part of this first group, and the number of responses, person responding, timeframe, and category of response were recorded and studied. Of the 10 letters, two fax-back-forms were returned, three telephone calls were received, four diagnostic reports were submitted, and EHDI staff contacted one PCP by phone. Nine of the 10 children could then be documented as having completed follow-up. The one outreach call made did not have an apparent impact, as that child was deemed "lost."
Act: Adapt testing plan.

Plan (Round 2): Several adaptations were implemented during the second round of testing: The timeframe was modified to six weeks post-screening in order to target PCPs prior to the babies' 2-month well-visit, and families who live out-of-state were left out of the group receiving tracking letters.
Do: In mid-September four letters were sent to parents and PCPs of babies born between 7/16/13 and 7/31/13, who did not pass newborn hearing screening and had no documented follow-up. The same data was recorded.
Study: Of the four letters sent as part of the second group, one fax-back-form was returned and one call was received; both these babies were documented as having completed follow-up as a result. EHDI staff also initiated phone calls to the PCPs of the two babies with no response and these babies are still pending.
Act: Adapt testing plan.

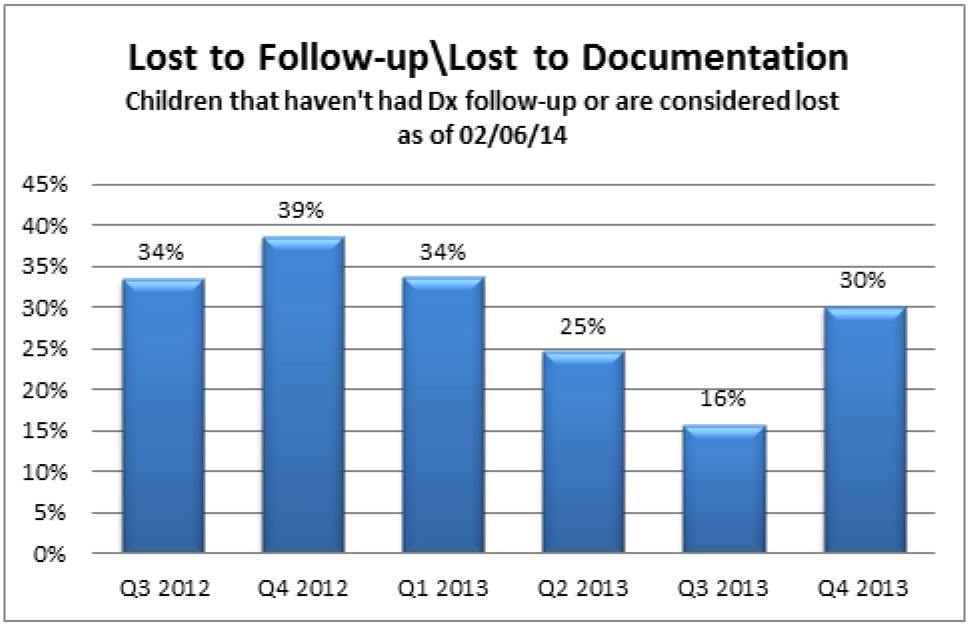
Plan (Round 3): Based on the examination of Round 2 results, EHDI staff realized that a more thorough review of cases was needed prior to sending letters. It was determined that the criteria for when to send letters needed to be based on a combination of factors. The criteria are:

1. Letters sent are based on the most recent screening date, instead of the birth date, as previously done. It was discovered that, in some cases, the most recent screening date was several weeks after the birth due, for example, to medical complications.
2. EHDI staff also reviewed case medical history, as found in the Maven: NSS, to determine if a child was still hospitalized, thereby having a legitimate reason for not meeting screening requirements. No letter will be sent, but the case will remain active and a letter will go out as needed.

3. A review of the screening history is conducted to see if an audiological follow-up appointment date was entered into the Maven: NSS. In some cases, this is entered by a hospital. If the appointment date has passed, EHDI staff will contact the audiology department to see if they failed to submit documentation. If the child was a "no show" on the appointment date, a letter will be sent.
4. Finally, staff had to allow for a reasonable amount of time for the family to follow-up prior to sending a letter.

Do: Seven letters were sent to the parent and PCP of babies born between 8/1/13 and 8/30/13.
Study: Two fax-back-forms were returned, three phone calls received, and two phone calls had to be initiated by EHDI staff; all seven could then be documented as complete.
Act: Many additional rounds of testing and studying the results of these tracking letters have occurred. Additional adaptations include: studying the apparent success of faxing a follow-up fax-back-form to the PCP's office within one month of sending the initial letter to confirm whether the child is still seen in that practice rather than a follow-up phone call due to time constraints and resource limitations; EHDI staff also correspond with audiology centers around the state that have been identified in returned physician fax-back-forms to obtain diagnostic results; and adjustments were proposed to Maven: NSS workflows in order to "skip" tracking letters for certain cases, such as families who live out-of-state. 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. To-date tracking letters have gone out regarding 83 babies and 44 of these babies are now documented as having completed follow-up (53%). In 11 cases, the hospital had reported the screening results incorrectly, these babies had passed their hearing screening prior to discharge. Three babies were rescreened within the medical home. Seven had been seen by an audiologist but the audiologist had not reported the results to the state EHDI program. The remaining group had follow-up that fell into a category that included an unknown delay.

Since initiating the tracking letter PDSA, EHDI staff monitor statewide LTF/D data on a quarterly basis. The percent of infants LTF/D by quarter is shown in the graph below:



This graph depicts a declining trend in LTF/D rates between the end of 2012 and throughout 2013, which is seemingly a result of both: 1) CT's participation in the IHSIS Learning Collaborative between June 2012 and September 2013, as many of the strategies the CT team developed focused on reducing LTF and increasing diagnostic reporting to the state EHDI program and 2) the aforementioned and ongoing tracking letter PDSA model for improvement. This PDSA will continue in order to ascertain any trends related to birth facility or audiology center, and until which time standardized fields can be incorporated within the Maven: NSS to better document response rates and identify specific areas for further quality improvement interventions. The changes tested during CT's participation in the IHSIS Learning Collaborative are outlined in *Attachment 7: Summary Progress Report*.

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 CT 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 CT are those whose home environments have multiple, recurrent, and unrelenting challenges. Children living in poverty face extensive health problems and family stress factors. Adding to the challenges, more young children live in poverty or near poverty, facing obstacles that impinge on their life choices before they enter kindergarten. Growing numbers of young children in CT 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 CT. 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. CT 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. In light of these disparities, continued collaboration between the EHDI Program and other early childhood programs targeting families in at risk communities is essential.

METHODOLOGY

Project Goal/Aim: By August 31, 2017, CT EHDI will use quality improvement methodology so that lost to follow-up/documentation of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery as reported through the CDC annual EHDI survey declines from a state average of 35% (2012 annual data) to a state average of 20% (2015 annual data).

In order to succeed in the aim stated above, the CT EHDI Program will implement targeted strategies of improvement in screening referral (did not pass) results, appropriate and timely follow-up and documentation of hearing diagnostic evaluations, identification of permanent hearing loss, and enrollment in early intervention, under the following aims:

Aim 1: By August 31, 2017, each of the 29 CT birth facilities and one licensed midwife practice will demonstrate individual hearing screening rates equal to or greater than 99% and a referral rate of less than 4% of the total infants screened by their facility.

There are four explanations for why infants do not have documented screening results, aside from parent refusal or infant demise: 1) a baby was born at home and a hearing screening was not conducted or the results were not shared with DPH; 2) a baby was born in a CT birth facility but was transferred to an out-of-state facility for additional care prior to being screened; 3) a baby was born in a CT birth facility but due to medical problems was transferred to a long-term medical floor and the hearing screening was missed or not shared with DPH; or 4) a baby was screened for hearing loss but the results were not entered in the Maven: NSS.

Change/Activity 1.1: Continue the Newborn Screening Homebirth Information Fax-Back-Form PDSA.

Plan: Now that the EVRS data matching and import process is in place, EHDI data includes demographic information on all babies born in CT. However, matching newborn screening results received to the appropriate vital record still presents some challenges. Newborn Screening, birth defects registry, and EHDI staff developed the following change strategy to address these challenges: For the next 20 babies, if a newborn screening bloodspot specimen is submitted to the DPH Laboratory by a pediatric provider or midwife for a baby born at home, the lab sends a fax-back-form back to that provider to gather additional demographic information to help match that baby to the correct EVRS record, including time of birth, birth order, and mother’s contact information, as well as requesting birth defects data and hearing screening results.

Do: This process began December 1, 2013, and to-date, the Lab has sent 15 providers the home birth form.

Study: Eight providers have returned the form, and 4 (50% of the returned forms) provided hearing screening results for the infant. Once five more forms are sent out, this stakeholder group will meet to discuss any observations and decide how to adjust the process in order to improve the response rate.
Act: At this point the group will decide what to do next – adapt (improve the change and continue testing), this may include a second fax request or a separate outreach letter from the EHDI Program to the family or PCP identified on the form; adopt, roll the change out to every subsequent home birth; or abandon and start a new approach to addressing this aspect of the above stated Aim, such as outreach to providers who returned the form but indicated there were no documented hearing screening results.

Change/Activity 1.2: Identify strategies to address border baby results sharing. When infants are transferred to an out-of-state facility for additional care prior to being screened, the CT EHDI Program does not typically receive their screening results, which can impact access to follow-up services and contribute to LTF/D. These babies are often premature/low birth weight or babies who are medically fragile and in a higher risk group for hearing loss.

Plan: Massachusetts has invited CT, the remaining New England states, and New York to participate in quarterly conference calls to collaborate and share quality improvement work taking place throughout the region. One of the priorities of these calls will be to identify improvement strategies focused on earlier access to border babies' hearing screening results. Strategies will include identifying border babies at the time they are initially transferred to an out-of-state facility and testing ways to obtain inter-state results as quickly and efficiently as possible. Staff from the EHDI program will review 2013 out-of-state transfer data and will initially focus on babies transferred to Massachusetts facilities initially because, predictably, these babies make up the largest cohort of missing hearing screening results. This planning phase will be followed by:
Do: Trying the change; Study: Observing the results; and Act: Acting on what is learned.

Change/Activity 1.3: Identify strategies at one facility to better track neonatal intensive care unit (NICU) babies transferred to a long-term medical floor who are missing hearing screening results. The audiology department at this facility is responsible for hearing testing of babies on long-term care units. Two audiologists at this facility were given access to the Maven: NSS and trained on entering newborn hearing screening results. Moving forward, discussions will be initiated to determine how many babies on long-term care floors are still missing documented hearing screening results and a plan will be developed to test small changes to address hearing screening documentation among this population.

Change/Activity 1.4: Continue to monitor the percent of infants not passing the hearing screen by individual birth facility and provide technical assistance and staff education.

As described under the Needs Assessment section, a statewide data analysis showed, 18 of Connecticut's 30 birth facilities regularly monitor their hearing screening workflows. The most common issues, which were identified through an analysis of the aforementioned workflows and individual hospital referral rates, are as follows:

1. A first and/or second hearing screening was performed but not documented in the system.
2. Two hospitals had referral rates that exceeded 4%.

During the Fall of 2013, the EHDI staff provided technical assistance, in the form of site visits or scheduled telephone conferences, to eight birth facilities aimed at improvements in these areas. Upon further examination, it was apparent that some hospitals needed to identify staff responsible for the weekly monitoring of their workflows to ensure accurate data reporting. Additionally, some hospitals needed re-training regarding newborn hearing screening referral protocol and data entry requirements; specifically, if a baby does not pass the first screening, a second screening should be conducted prior to discharge and documented as such in the system. Furthermore, EHDI staff identified one challenge in the workflow design – After 120 days of inactivity, a baby's record will "close" and automatically fall off of the workflows, even if the case is still missing data. This is a necessary feature because if the workflow lists contain a large number of records, it negatively impacts system performance. Alternatively, these babies are captured on a new custom Maven: NSS report called, NSS Hearing Screening – No Test No 2nd Test, which was designed and implemented during the first part of Year 3. This report is only accessible to EHDI staff but its details are provided to individual birth facilities as needed to capture missing data outside of the 4 month workflow timeframe.

To address the second issue of referral rates over 4%, EHDI staff conducted multiple technical assistance sessions both in person and via phone in order to work with each birth facility to improve their internal procedures. An informal written plan of correction is required from one hospital because their AABR screener broke; thus they are only using OAE screening equipment, which fails to meet CT's newborn hearing screening best practice guidelines. As a result this hospital had an 11.5% referral rate in 2013. The other facility, with a 5.1% referral rate in 2013, needed to provide additional staff education regarding screening procedures and data entry protocol. Additional improvement strategies related to the use of hospital workflows and reports will be studied.

All four activities described above will be measured based on the following process and outcome measures:

Process Measures:

- 100% of CT birth facilities (29) and the one licensed midwife practice will electronically report newborn hearing screening data to the DPH via the Maven: NSS, including out-of-state transfer facility information. Hospital staff and state EHDI staff will monitor screening workflows for compliance.
- Lab staff will continue to send home-birth forms and record the number sent and EHDI staff will track the number received and percent that included hearing screening results.

Outcome Measures:

- Percent of infants screened
- Percent of infants within the following categories:
  - Born at home with documented hearing screening results

  - Transferred to an out-of-state hospital with documented hearing screening results
  - Transferred to a long-term care floor with documented hearing screening results
- Percent of infants not passing final hearing screening statewide and by individual birth facility

Aims 2: By August 31, 2017, 80% percent of infants who do not pass their hearing screening will receive an audiological evaluation by 3 months of age (90 days) and the results of this evaluation will be shared with the State EHDI Program.

Change/Activity 2.1: Test the use of a physician fax-back-form in higher risk groups to determine its impact on LTF/D.

EHDI staff will select one facility to target based on a referral rate closer to 4% and with poor follow-up rates (greater than 50% LTF/D after failure to pass newborn hearing screening). EHDI staff will send a modified version of the previously developed physician fax-back-form to the infant's primary care provider (PCP) of record within a week of the child's final screening date, prior to the regular tracking letter, to determine if an earlier notification impacts follow-up timeframes and rates. The effectiveness of this additional PCP contact mechanism will be studied based on the measures below, and the process will be modified accordingly. If the EHDI team is confident the intervention has led to improvement, it will be spread to additional hospitals based on individual facility referral and follow-up statistics.

Process Measures:
- Birth facilities will report newborn hearing screening results within a week of the screening date

Outcome Measures:
- Percent of infants evaluated by 3 months of age
- Percent infants with permanent hearing loss diagnosed by age 3 months
- Percent of infants who failed their hearing screening and are lost to follow up/documentation (LTF/D) for diagnosis

Change/Activity 2.2: Continue implementing the spread of a successful change strategy as identified through CT's participation in the NICHQ Learning Collaborative: Referrals given direct appointment with audiology.

One of the strategies CT's IHSIS team studied was giving families an audiology appointment date before they leave the hospital with their baby after failure to pass newborn hearing screening. By making a "direct referral" to audiology before discharge, the results showed families were scheduled in half the number of weeks than had previously occurred and all the families kept their appointments. This approach will be spread to other hospitals as a proven strategy for improving LTF/D. Currently, 15 hospitals indicate they schedule audiology appointments with families prior to discharge. The focus will be on spreading this change to the remaining 14 hospitals that to not consistently schedule appointments prior to discharge. The hospitals with the highest individual LTF/D rates will be targeted first.

Outcome Measures:

- Percent of infants who do not pass their hearing screening,
    - who receive follow-up testing
    - who are lost to follow up/documentation (LTF/D) for diagnosis
- Percent of infants evaluated by 3 months of age

Change/Activity 2.3: Additional discussion with the stakeholder team will include planning specific interventions that address decreasing the number of infants who remain with a diagnosis in progress.

EHDI staff plan to add a custom report to the Maven: NSS to facilitate better tracking of infants who have a diagnosis in progress, or in other words have connected with an audiology center but lack a complete diagnosis, including broken appointments, scheduled appointments, and inconclusive results. Once a custom "In Progress" report is designed and implemented, the data will be used to develop a change strategy that includes communicating outstanding diagnostic results. For example, this may take the form of a monthly data report to audiological centers to increase the number of diagnostic evaluation reports sent to DPH. Then, opportunities for spreading the identified changes to other facilities will be explored if proven successful in addition to the possibility of making this type of report available for audiologists to generate for themselves within the system.

Process Measures:

- Send a monthly data report to audiologists identifying infants previously seen at their center without a final diagnosis

Outcome Measures:

- Percent of infants who do not pass their hearing screening,
- Percent of infants who receive follow-up testing
- Percent of infants who remain with a diagnosis in progress
- Percent of infants who are lost to follow up/documentation (LTF/D) for diagnosis
- Percent of audiological diagnostic evaluation results reported to State EHDI Program

Aim 3: By August 31, 2017, 95% of infants with identified hearing loss will be referred to Birth to Three.

Change/Activity 3.1: Continue the physician-to-physician coaching project that began in 2011 with the intent of providing outreach and education to child health providers (PCPs) who care for children newly diagnosed with hearing loss. Physician coach, Brenda Balch, MD, contacts all PCPs of babies diagnosed with hearing loss in CT. Dr. Balch reviews recommended follow-up services and works with PCPs to facilitate obtaining services for that baby. This project engages PCPs in the implementation of American Academy of Pediatrics EHDI guidelines and facilitates connections to EI, genetics, otolaryngology, ophthalmology, and family support services. As Dr. Balch has contacted PCPs, CT has been able to document an increase in the number of babies with identified hearing loss being referred to early intervention, as presented in the Needs Assessment section of the application. This project has gone through multiple phases. Dr. Balch worked to streamline the follow up letter content in order to cater to individual needs of each physician, and she developed and tested a fax-back-form as part of the NICHQ Learning Collaborative. As a result, Dr. Balch adopted the following protocol: Contact all PCPs with infants diagnosed with HL a maximum of three times (letter initially and then fax requests no more than twice) to obtain information regarding timely referral to EI and subspecialists. Additionally she does not request a fax form to be completed if the infant has been enrolled in EI before 6 months of age and appropriate subspecialty consultation has already taken place. Dr. Balch is also exploring ways to collect qualitative data on this coaching project and opportunities for improvement will be examined based on these conclusions. From a statewide data perspective, since the physician-to-physician coaching project began in 2011, Birth to Three referral rates have increased as show in the table below:

Year	Percent of children with Hearing Loss Referred to Birth to Three
2009	70.1%
2010	73.5%
2011	90.1%
2012	84.0%

Process Measure:

- DPH sends monthly reports to Birth to Three that include the names of children who have been diagnosed with hearing loss but for whom enrollment in early intervention has not been confirmed. Based on the terms of the Memorandum of Agreement between both state agencies, Birth to Three provides the following data for each child: date of referral, referral source, eligibility status, date of eligibility, date of enrollment, and Birth to Three Program name.

Outcomes Measures:

- Percent of infants with hearing loss referred to Part C Early Intervention (EI) – CT Birth to Three
- Percent of infants diagnosed with permanent hearing loss, of any severity, that are referred to and have access to high quality intervention services.

Aim 4: By August 31, 2017, 85% of infants will be enrolled in EI by 6 months of age and their date of entry will be shared with the State EHDI Program.

Change/ Activity 4.1: A change strategy was identified to decrease the amount of time between referral and subsequent enrollment in Birth to Three due to delays in obtaining the diagnostic evaluation report.
Plan: An area for improvement was identified during the January 2014 EHDI Task Force/QI team meeting: A Birth to Three Program cannot begin delivering early intervention services to a

child with hearing loss until the program obtains the diagnostic audiology evaluation report. There are barriers to timely receipt of diagnostic reports, which delays enrollment.
Do: For the next five children pending enrollment, when a Birth to Three hearing specialty program director requests a diagnostic report from an audiology facility's medical records department, she will also notify the Audiology Manager and diagnosing audiologist, when identified, at that audiology center of her request.
Study: The response timeframe will be documented and the QI stakeholder group will examine whether the audiology department's involvement in the process impacted outcomes.
Act: A determination will be made whether additional protocol changes could also have an impact.

Once a successful strategy is identified, opportunities for spread to the third hearing specialty center and additional audiology centers will be explored and implemented.

Change/ Activity 4.2: Change strategies will be identified to develop and use resources, such as parent roadmaps, to ensure families are knowledgeable about the EHDI system and "next steps."

The QI stakeholder team includes parents and several members of CT Hands & Voices. A new contract with CT Hands & Voices is being proposed to help facilitate the development of parent-focused resources aimed at both guiding families through the EHDI process by breaking down potential barriers as well as providing families with information about family-to-family support at the point of EI referral.

Aim 4 Process Measure:
- DPH sends monthly reports to Birth to Three that include the names of children who have been diagnosed with hearing loss but for whom enrollment in early intervention has not been confirmed. Based on the terms of the Memorandum of Agreement between both state agencies, Birth to Three provides the following data for each child: date of referral, referral source, eligibility status, date of eligibility, date of enrollment, and Birth to Three Program name.
- Develop parent resources aimed at expanding knowledge of EHDI process and providing family-to-family support resource information at the point of referral to early intervention.

Aim 4 Outcome Measures:
- Percent of infants enrolled in EI by 6 months
- Percent of infants enrolled in EI who have date of entry reported to State EHDI Program
- Families are linked to needed intervention and support services no later than age 6 months

Supporting Activities:

- Distribute program brochures to CT birth facilities, including the "*Listen Up*!" and "*A Parent's Guide to Diagnostic hearing Testing of Infants*" pamphlets
- Develop and distribute additional parent resources during the prenatal period, such as through obstetrician's offices and child birth education classes.

- Provide ongoing Maven: NSS user account and data entry support, as needed
- EPIC (Educating Practices in the Community) module on EHDI – developed by the Child Health and Development Institute of CT (CHDI), in collaboration with DPH, with the intent to improve quality of care related to hearing loss among pediatric-age patients in the primary care setting. CHDI will continue to present the EHDI EPIC module to primary care practices, including practices in each of the state's five CYSHCN Program service areas, and provide each practice with tools and resources to ensure better outcomes in the medical home for children who are deaf or hard-of-hearing.
- Develop collaborative partnerships with other early childhood programs, including Maternal, Infant, and Child Home Visiting Program and Head Start/Early Head Start.

The EHDI Program works to involve the infant's primary health care provider and to facilitate parent-professional partnerships to support a medical home approach to providing health care services: Care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

CT EHDI Task Force (advisory committee)

Connecticut has a well-established EHDI Task Force (essentially serves as an informal advisory committee), which was instrumental in getting the necessary legislation passed to implement universal screening in CT. The Task Force is a multidisciplinary group of professionals with representation from the following: DPH, state Birth to Three system, audiologists, American School for the Deaf, CREC/Soundbridge, NECHEAR, otolaryngologists, parents of children who are deaf or hard of hearing, members representing the deaf and hard-of-hearing community and other community-based representatives who work with the deaf and hearing impaired population. The Task Force meets on the first Thursday of each month, has worked collaboratively with the CT DPH for 15 years, and remains an active force in the EHDI program.

Quality improvement was added as a standing agenda item in September 2013, and the membership is involved in identifying EHDI system aims and identifying change strategies. All but two of the 13 CT IHSIS Learning Collaborative state team members still regularly participate in monthly meetings. See Attachment 4: *QI Team* for a list of members and their organizational affiliations.

Sustainability Plan

Connecticut General Statutes, Section 19a-59 ensures universal hearing screening of all newborns at the birth facility-level and independent of Federal funds; "Each institution, as defined in section 19a-490, that provides childbirth service shall, no later than July 1, 2000, include a universal newborn hearing screening program as part of its standard of care and shall establish a mechanism for compliance review." Additionally, "The Department of Public Health shall establish a plan to implement and operate a program of early identification of infant hearing impairment….[and] the Commissioner of Public Health shall adopt regulations, in accordance with Chapter 54, to implement the provisions of subsection (a) of this section." Regulations do exist in the Public Health Code, and include a provision for reviewing implementation of Section 19a-59-1 of the Regulations of Connecticut State Agencies at the time of licensure inspections.

Additionally, the Maven: NSS is a shared database and costs can be distributed across programs. Birth facilities enter real-time data in the system and hospital users exceed 800, so cross-training is a priority on the birth facility-level. The automated link with EVRS and other automated features and custom reports have been built into the Maven: NSS, which also contributes to sustainability. Electronic audiology reporting is an upcoming priority and will be supported with CDC funding. Still dedicated staff time is critical to the success of the program, particularly as it relates to LTF/D. CT EHDI program staff are entirely federally funded at this point in time.

WORK PLAN

See Attachment 1.

RESOLUTION OF CHALLENGES

Although the proposed activities complement current initiatives underway in the CT EHDI system, there are a number of challenges to 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 ongoing.

The first challenge is ensuring the EHDI Program receives a record of every home birth in the state. Home births delivered by a Birth and Beyond midwife are electronically reported through the Newborn Screening System, which provides EHDI with partial data on home births. The two-way matching mechanism between EVRS and the Maven: NSS gives EHDI staff the ability to identify individual data on all out-of-hospital births in the state and is a step in the right direction in determining these infants’ screening status; however gaps in results reporting still exist. The changes discussed under Aim 1 speak to possible improvement strategies to address existing barriers.

Additional challenges 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 and/or address changes or a change in the PCP after discharge. The strategies proposed under Aim 2 are complicated if the PCP reported by the birth facility is inaccurate or the child’s responsible party identifies one provider but subsequently changes their mind post-discharge. This is an ever-present obstacle in locating children in any screening program; however over time this problem will be resolved, in large part, by data integration activities. The EHDI program is fortunate to now receive updated data from EVRS, which provides EHDI staff with an alternate name for the baby and address as reported on the birth certificate. Maven: NSS records will continue to be matched with EVRS data on a daily basis. Currently, if the PCP name recorded in the NSS is inaccurate, EHDI staff work with immunization staff to consult a child’s immunization record in order to identify which PCP administered the last vaccine to the child. Moving forward, the Maven: NSS instance (EHDI, Lab Newborn Screening and Tracking, BDR) will be linked with both the CYSHCN instance and the CT Immunization Registry; therefore, address, telephone, and PCP data fields will receive ongoing updates from multiple end users.

Lastly, all four proposed aims will only be successful if continued stakeholder involvement and buy-in remains strong. The proposed external partners, birth facilities, audiologists, Birth to Three, and Hands & Voices, have existing ties to DPH and a demonstrated history of effective teamwork. Relatively high Nurse Manager turnover at birth facilities presents some challenges, but the majority of hospitals train at least five Maven: NSS users, so even when leadership changes hands, there is typically enough continuity of staff to maintain data reporting elements. There are gaps in pediatric audiology services, particularly in the western part of the state, because there are a decreasing number of audiologists experienced in working with infants and young children. The southwest region of the state has limited access to an infant diagnostic testing location and transportation presents a problem for some families. Audiologists from the three hospital-based diagnostic centers that conduct the majority of follow-up testing in the state regularly and actively participate on CT's QI Team. The MOA between the state agencies that house the EHDI Program and Birth to Three helps facilitate monthly data exchanges; however, it will be important to maintain dedicated staff resources to support this ongoing relationship.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Plan for Program Performance

The Maven: NSS will be used as the primary tool in this evaluation to monitor the ongoing progress and the processes of this project. In addition to being a repository for data, the NSS also has extensive reporting capabilities used by staff for tracking, follow-up, in-depth analysis, and evaluation of program activities. The NSS is updated daily, enabling the EHDI program an exceptional amount of flexibility and responsiveness to use its data to review progress and make changes to program activities, if needed, as trends or concerns arise.

Additionally, monthly scheduled meetings with collaborative partners and more frequent voice or electronic contact with collaborative partners will be used in this evaluation to monitor ongoing progress and processes to affect program performance.

Also, EHDI staff, along with its collaborative partners, have also recently completed a learning collaborative with the National Initiative for Children's Healthcare Quality (NICHQ).

This project will be evaluated at various stages of the proposed project. The evaluation of the individual activities described in this project will be conducted by EHDI staff and is outlined under each specific aim 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 20% or less by 8/31/2017.

Experience, Skills, Knowledge of Staff, and Published Works

Amy Mirizzi, MPH, CPH, Health Program Associate, serving as the Principal Investigator, was hired in 2005, with primary responsibility for EHDI tracking and surveillance. This included: database design, maintenance, and management: data analysis and interpretation; program monitoring; and the creation and the implementation of quality assurance techniques to meet program goals and to ensure hospital compliance with CT's universal newborn hearing screening statute. Since June 2008, Ms. Mirizzi has served as the CT EHDI Coordinator and is a member, and past chair, of the CT EHDI Task Force, the Commissioner's designee to the Department of Rehabilitation Services [Deaf and Hearing Impaired] Advisory Committee, 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 CT Department of Developmental Disabilities - Birth to Three System, and the CYSHCN program. Ms. Mirizzi is responsible for the overall program operations, including policy development, technical support to hospitals and diagnostic testing centers, consultation on database design and development, education and outreach, family education, cultural competency, and ongoing program evaluation. Ms. Mirizzi will continue to take the lead role in the maintenance of ongoing quality assurance mechanisms, implementation of quality improvement methodology, outreach and education initiatives, database and reporting modifications and improvements, hospital technical assistance needs, evaluation and data analysis activities associated with this project, and training staff and collaborative partners as needed.

John Lamb, Health Program Assistant 2, hired in 2012, is responsible for assisting with Maven: NSS data entry, data analysis, lost to follow-up/lost to documentation (LTF/LTD) tracking and surveillance activities, and work flow technical assistance to CT birth facilities, including ongoing day-to-day technical and programmatic support. Mr. Lamb also assists with quality assurance, coordinating ongoing hospital newborn hearing screening data reporting, programmatic training, and technical assistance. Additionally, he also assists and works with Consilience on Maven: NSS enhancements as well as on updates to decision support tools, such as workflows and reports, and acted as data manager for the NICHQ IHSIS Learning Collaborative.

Ann Gionet, part-time Health Program Associate and Family Advocate, works 12 hours/week devoted to EHDI activities. Ms. Gionet has worked in the CYSHCN Program for the last for 19 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 also has expertise in CT's work to address autism spectrum disorders and developmental screening in the pediatric medical home. 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.

The CT EHDI program has published, both in print and electronically, an array of educational and informational materials for families and providers that supports all aspects of EHDI. 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 Parent's 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 English and Spanish and are available in hard copy as well as on the EHDI website, which is in the process of being completely renewed. EHDI staff have also created a printable flowchart, available on the website, to help parents navigate the hearing screening process. EHDI Program staff, in collaboration with the CT EHDI Task Force, have developed a resource, called: "*What YOU Need to Know about Providing Health Care for Infants & Young Children with Hearing Loss*." Written for PCPs, EI providers, and medical home/CSHCN care coordination networks, it includes information about risk factors for hearing loss in childhood and appropriate monitoring and follow-up protocol.

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 website. The service guideline is given to all families at the time of referral to EI.

The EHDI program is distributing two national resources developed by the National Center for Hearing Assessment & Management: "*Communicate with Your Child*" pamphlet for parents of a newly diagnosed young child, and a Newborn Hearing Screening Training Curriculum DVD designed to assist birth facilities with ongoing competency-based training.

ORGANIZATIONAL INFORMATION

Applicant Organization: Mission, Structure, Scope, Organizational Chart, and how these Contribute to EHDI Meeting Program Expectations

The CT DPH is the lead agency for the state's public health initiatives. DPH's mission is to protect and improve the health and safety of the people of Connecticut by: Assuring the conditions in which people can be healthy; Preventing disease, injury, and disability; and

Promoting the equal enjoyment of the highest attainable standard of health, which is a human right and a priority of the state. The Department's vision is "Healthy People in Healthy Connecticut Communities." The scope of DPH can be broken down into three areas: Ensures a safe and healthy environment; Promotes good health and prevents injury and disability; and Prevents the spread of disease.

Organizationally speaking, the EHDI program is a subset of the Family Health Section (FHS), which in turn is one of 14 sections, branches, or offices that serve under the DPH umbrella. The branch consists of the following sections: Community Health and Prevention; Family Health; and Infectious Diseases. The Family Health Section consists of the following programs: EHDI, CYSHCN; Primary Care Office; School and Adolescent Health (school-based health centers); Community Health Centers, Sickle Cell Disease Education; Case Management for Pregnant Women; the Birth Defects Registry; Maternal, Infant, and Early Childhood Home Visiting; Sexual Violence Prevention; Family Planning; and Healthy Start. On a federal level, the CT'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.

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

Program Resources and Capabilities to Support Culturally and Linguistically Competent Services

CT has a well-established EHDI Task Force, which was instrumental in getting the necessary legislation passed to implement universal screening in CT. The Task Force is a multidisciplinary group of professionals with representation from the following: DPH, Birth to Three, audiologists, the American School for the Deaf, otolaryngologists, parents of children who are D/HoH, other community-based representatives who work with the target population, as well as members of the deaf community whom themselves are D/HoH.

The DPH EHDI website is dedicated to culturally competent and linguistic health services by offering numerous written guidance, brochures, points of contact, links to organizations, and other resources to assist the parents of children that have not passed their hearing screening tests or their diagnostic hearing evaluation. Also, the site has been equipped with a Google Translator feature for 80 languages.

The EHDI program also has access to American Sign Language (ASL) interpreters from a community partner, and has in-house volunteer foreign language interpreters.

The EHDI program also has access to a former EHDI program team member, Kathy Britos-Swain, MSN, who is an RN and is also bilingual. Her medical ability, understanding of EHDI, combined with her exceptional Spanish language skills, has been and remains a valuable resource to the EHDI program's goal of culturally and linguistically competent services to constituents. Ms. Britos-Swain has also assisted numerous times with interpreting or transcribing English brochures to Spanish and has been available to answer phone calls to Spanish speaking customers. She remains available, on an as needed basis to continue assisting EHDI.

Describe how the Needs of the Target Population Served are Routinely Assessed and Improved

To understand how the program ensures the unique needs of the target population are assessed and improved routinely, one must first know the integral programmatic goals: All newborns to be screened for hearing loss at birth before hospital discharge, for diagnostic testing to be completed by 3 months, and if diagnosed, for the baby to be enrolled in Birth to Three for EI services by 6 months of age.

CT EHDI, on a daily basis, assesses the success of the reporting system responsible for reporting all newborn birth screenings through:

- the daily analysis of screening documentation that the program receives through direct electronic reporting by birth facilities through the Maven: NSS, or alternatively via faxes, phone calls, or emails, regarding newborn hearing screening results. As this data is entered in Maven: NSS, a quality check of the data is made to ensure its veracity and that both established and accepted procedures are followed. This check includes accuracy of demographic information, date checks, and a determination is made if the correct procedures were followed. For example, in some cases it has been discovered during these quality reviews that a screening was missed, or done improperly. As a result, the policy is reviewed to determine if it needs adjustment, or if the case concerned merits special dispensation. If not, the facility is contacted and the error is discussed in an informal verbal training. If enough errors occur, a call to a supervisor or an on-site retraining is conducted to ensure procedures are understood and followed, thereby improving the target populations' services.

- a monthly review of a "screening workflow," which has been built into Maven: NSS to track birth cases that are missing the appropriate screenings. A monthly review of this workflow is conducted by program staff, which ensures newborns, without adequate reasons, medical concerns for example, are receiving the appropriate screenings at birth. Phone calls, emails, or faxes are sent to birthing facilities that have not reported per procedure requesting a reason why the screening was not conducted, why or how lack of documentation occurred, or to request a copy of the screening. Again, if a pattern emerges by any one birthing facility, a retraining is conducted.

Ensuring diagnostic testing by three months of age was a substantial component to the EHDI program's NICHQ collaborative and remains a topic for both discussion and improvement during internal meetings and at task force meetings.

- An assessment of a past EHDI tracking system, which had been used to address lost to follow-up cases, was made to determine if a revised procedure could improve the percentage of newborn (target population) receiving diagnostic testing by three months of age. Program staff concurrently developed both a new protocol and tools to address this goal. This new protocol called for a new internal database (Excel) to be created, as well as new template letters to be sent to the parents and PCPs of the concerned newborns, with the goal of improving the lost to follow-up percentage. Specifically, an Excel database tracks all children since July, 2013, whom had not had the appropriate diagnostic evaluation by seven weeks of age. This age was picked due to the timing of well-baby visits and to account for a distinct lag in submission of audiological documentation from providers. Additionally, the template letters were improved to be in both English and Spanish, and to also contain information on where parents and PCPs could turn for more information, a list of testing centers, an explanation of the importance of testing, and a contact number for parents who are un\under-insured. The letter also asked parents and PCPs to contact CT EHDI if there child did pass a diagnostic evaluation. Between 07/01/13 and 02/03/14, the EHDI program has been able to close out 56% of all the cases that would have otherwise been classified as lost to follow-up due to this improved tracking system and template letters.

- As part of the NICHQ collaborative, CT EHDI worked with its community partners, whom were also a part of the collaborative, to improve, or in some cases, develop methods to address the percentage. Several birthing facilities began providing hand-outs or a written reminder to parents explaining the importance of the diagnostic evaluation, while other made internal changes to allow nursing staff to make a follow-up diagnostic appointment before the newborn leaves the hospital.

Enrollment in Birth to Three for EI services by 6 months of age is another critical goal of CT EHDI and is frequently reassessed to ensure our target population is receiving the proper services.

- CT EHDI works closely with the Department of Developmental Services' (DDS) Connecticut Birth to Three System (B23) coordinator to review cases of newborns and infants with documented hearing loss to determine if referral to, or services from, a Birth to Three program has been made. The coalition of DPH EHDI staff and the DDS B23 coordinator meet quarterly, at a minimum, excluding the monthly task force, but meet more frequently as needed to assess the effectiveness of this coalition in regards to ensuring the target populations' services received are adequate. During these meetings, an informal review and assessments are made. As a result:

- At the behest of DPH EHDI and DDS B23 staff, a new MOU was created, which now allows for deeper sharing of information between the two agencies, thus allowing better tracking of services by EHDI
- It was determined through coalition meetings and the NICHQ collaboration, that not all data was being reported, as required, by audiologists. As a result, EHDI revamped and reintroduced the child case information form used by B23 programs. This form is submitted to DPH, in conjunction with the parent release, mentioned below, by the B23 provider. The form is primarily used to capture diagnostic evaluation information, which in many cases would have been lost to documentation. In some instances, the form also provided the most recent diagnostic evaluations conducted by B23 programs, where before EHDI would have only had access to hearing centers' reports, which while valid, were not necessarily the most recent. Also, other data is captured on these forms including: Dates of referral and eligibility for B23 services, types of amplification devices provided, and the dates of amplification.
- The reintroduction of a personal information release form was also made. The form is used by B23 providers, such as the American School for the Deaf, which, when signed by parents, allows a B23 program permission to share child case data with EHDI. This is used in conjunction with the above release form.
- Coalition procedures were also reassessed resulting in the elimination of redundant effort. As mentioned, a quarterly meeting takes place between DPH EHDI and DDS B23. At these meetings, EHDI presents a list of infants in need of B23 services and, in turn, B23 staff provides data pertinent to each case. A new process is being fielded that reduces time spent, and duplicative effort.
- The EHDI program also houses and oversees the MD to MD program. This is a physician run program that contacts the pediatricians of newborns and infants that are D/HoH, which have not received B23 services, to provide education, outreach, and technical assistance. Reassessment of this program has streamlined the process by better prioritizing child cases, thereby freeing up the MD to contact pediatricians of children at critical junctures improving services.

It is necessary to continuously address these topics on an individual basis, such as through site visits and chart reviews and statewide through annual educational conferences. All are crucial opportunities to bring the newborn hearing screening, diagnostic, and EI components together in order to enhance overall clinical and administrative procedures and maximize the benefit to families around the state.

Previous Experience Executing and Implementing QI Projects

Connecticut participated in the National Initiative for Children's Healthcare Quality (NICHQ) Improving Hearing Screening and Intervention Systems (IHSIS) Learning Collaborative, from June 2012 to September 2013, during which time program staff learned how to use quality improvement methodology to identify small programmatic changes that result in documented improvements in infant follow-up outcomes. The CT team used PDSA cycles to test a variety of strategies, which are outlined in Attachment 7: *Summary Progress Report*.

Attachment 1: Work Plan

Activities/ Strategies related to the following Goals/Aims and Objectives/Aims will be implemented to achieve the activities proposed in the methodology section:

Project Goal/Aim: By August 31, 2017, CT EHDI will use quality improvement methodology so that lost to follow-up/documentation of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery as reported through the CDC annual EHDI survey declines from a state average of 35% (2012 annual data) to a state average of 20% (2015 annual data).

Aim 1: By August 31, 2017, each of the 29 Connecticut birth facilities and one licensed midwife practice will demonstrate individual hearing screening rates equal to or greater than 99% and a referral rate of less than 4% of the total infants screened by their facility.

<table>
<tr><th>Changes/Activities</th><th>Timeline: Start Date – Estimated Completion Date</th><th>Outputs: <i>Process Measures</i></th><th><i>Outcome Measures</i></th><th>Lead Staff and Partner Support</th></tr>
<tr><td>1.1 Continue sending Newborn Screening Homebirth Information Fax-Back-Form</td><td>Multiple PDSA cycles anticipated (began 12/1/13) Estimated completion date: December 31, 2014</td><td>Lab newborn screening staff will continue to send home birth forms and record the number sent, and EHDI staff will track the number received and percent that included hearing screening results.</td><td>Percent of infants born at home with documented hearing screening results</td><td>Amy Mirizzi, EHDI Coordinator</td></tr>
<tr><td colspan="5"><u>Plan:</u> For the next 20 babies, if a newborn screening bloodspot specimen is submitted to the DPH Laboratory by a pediatric provider or midwife for a baby born at home, the lab sends a fax-back-form back to that provider to gather additional demographic information to help match that baby to the correct EVRS record, including time of birth, birth order, and mother’s contact information, as well as requesting birth defects data and hearing screening results. <u>Do:</u> This process began December 1, 2013, and to-date, the Lab has sent 15 providers the home birth form. <u>Study:</u> Eight providers have returned the form, and 4 (50% of the returned forms) provided hearing screening results for the infant. Once five more forms are sent out, this stakeholder group will meet to discuss any observations and decide how to adjust the process in order to improve the response rate. <u>Act:</u> At this point the group will decide what to do next – adapt (improve the change and continue testing), this may include a second fax request or a separate outreach letter from the EHDI Program to the family or PCP identified on the form; adopt, roll the change out to every subsequent home birth; or abandon and start a new approach to addressing this aspect of the above stated Aim, such as outreach to providers who returned the form but indicated there were no documented hearing screening results.</td></tr>
</table>

Changes/Activities	**Timeline: Start Date – Estimated Completion Date**	**Outputs:** *Process Measures*	*Outcome Measures*	**Lead Staff and Partner Support**
1.2 Identify strategies to address border baby results sharing	Multiple PDSA cycles anticipated Year 1: September 1, 2014 – August 31, 2015	Meet with New England regional QI group quarterly CT birth facilities electronically record out-of-state transfer facility information to facilitate surveillance activities	Percent of infants transferred to an out-of-state hospital with documented hearing screening results	Amy Mirizzi, EHDI Coordinator / John Lamb, HPA2 CT birth facility staff Massachusetts EHDI staff
1.3 Identify strategies at one facility to better track NICU babies transferred to long-term care floor who are missing hearing screening results	Year 2: September 1, 2015 – August 31, 2016	One CT facility electronically records babies transferred to long-term care floors within their facility	Percent of infants transferred to a long-term care floor with documented hearing screening results	Amy Mirizzi, EHDI Coordinator / John Lamb, HPA2 CT Children’s Medical Center staff, including audiologists
1.4 Continue to monitor the percent of infants not passing hearing screening by individual birth facility and provide technical assistance and staff education	Year 1 – Year 3: September 1, 2014 – August 31, 2017 Ongoing PDSA cycles to identify successful improvement strategies	Number of CT birth facilities monitoring hearing screening workflows on a monthly basis	Percent of infants not passing final hearing screening statewide and by individual birth facility	Amy Mirizzi, EHDI Coordinator / John Lamb, HPA2 CT birth facility staff
Broad description of PDSA Cycles, which can be applied to Changes/Activities 1.2, 1.3 & 1.4. Plan: Meet with Quality Improvement Team, analyze current data, and discuss strategic approaches to change; Do: Work with facilities identified to carry out change strategy; Study: Review facility’s next quarter data for improvement; Act: Based on outcomes, spread and apply change to other facilities. Consider additional PDSAs addressing above issues, as needed.				

Aim 2: By August 31, 2017, 80% of infants who do not pass their hearing screening will receive an audiological evaluation by 3 months of age (90 days) and the results of this evaluation will be shared with the State EHDI Program.

Changes/Activities	**Timeline: Start Date – Estimated Completion Date**	**Outputs:** ***Process Measures***	***Outcome Measures***	**Lead Staff and Partner Support**
2.1 Test the use of a physician fax-back-form in higher risk groups to determine its impact on LTF/D. Identify a birth facility with both a referral rate around or greater than 4% as well as an individual LTF/D rate >50%.	Year 1: September 1, 2014 – August 31, 2015	Birth facilities will report newborn hearing screening results within a week of the date screened	Percent of infants evaluated by 3 months of age Percent of infants with permanent hearing loss diagnosed by 3 months of age Percent of infants who failed their hearing screening and are LTF/D	John Lamb, HPA2 Individual primary care providers
2.2 Continue implementing the spread of a successful intervention – giving infants who do not pass hearing screening direct appointments with audiology prior to discharge.	Year 1 – 2: September 1, 2014 – August 31, 2016	Fourteen hospitals that do not currently schedule audiology appointments prior to discharge will study ways to implement this change	Percent of infants who do not pass their hearing screening: - who receive follow-up testing - who are LTF/D Percent of infants evaluated by 3 months of age	Amy Mirizzi, EHDI Coordinator / John Lamb, HPA2 CT birth facility staff CT diagnostic audiology center staff
2.3 Plan specific interventions to address reducing the number of infants who remain with a diagnosis in progress.	Year 1 – 2: September 1, 2014 – August 31, 2016	Design and implement "In Progress" report in Maven: Newborn Screening System	Percent of infants who do not pass their hearing screening: - who receive follow-up testing	Amy Mirizzi, EHDI Coordinator / John Lamb, HPA2 CT diagnostic

		Audiologists sent monthly reports regarding infants without completed diagnostic evaluation – eventually given direct access to report in Maven: NSS	- who remain with a diagnosis in progress - who are LTF/D Percent of audiological diagnostic evaluation results reported to State EHDI Program	audiology center staff

Aim 3: By August 31, 2017, 95% of infants with identified hearing loss will be referred to Birth to Three.

Changes/Activities	**Timeline: Start Date – Estimated Completion Date**	**Outputs:** ***Process Measures***	***Outcome Measures***	**Lead Staff and Partner Support**
3.1 Continue physician-to-physician coaching project to provide outreach to PCPs who care for children with hearing loss.	Year 1 – Year 3: September 1, 2014 – August 31, 2017	DPH sends monthly reports to Birth to Three on children newly diagnosed with hearing loss to confirm early intervention enrollment outcomes Birth to Three provides the following data fields: – Date of referral – Referral source – Eligibility status – Date of eligibility – Date of enrollment – Birth to Three program name	Percent of infants with hearing loss referred to Part C EI – CT Birth to Three Percent of infants diagnosed with permanent hearing loss that are referred to and have access to high quality early intervention services	Amy Mirizzi, EHDI Coordinator / John Lamb, HPA2 Dr. Brenda Balch, AAP EHDI Chapter Champion CT primary care providers CT Birth to Three Program

Aim 4: By August 31, 2017, 85% of infants will be enrolled in EI by 6 months of age and their date of entry will be shared with the State EHDI Program.

Changes/Activities	**Timeline: Start Date – Estimated Completion Date**	**Outputs:** ***Process Measures***	***Outcome Measures***	**Lead Staff and Partner Support**
4.1 Implement strategies to address delays between referral and enrollment in Birth to Three	Year 1: September 1, 2014 – August 31, 2015	DPH sends monthly reports to Birth to Three on children newly diagnosed with hearing loss to confirm early intervention enrollment outcomes Birth to Three provides the following data fields: − Date of referral − Referral source − Eligibility status − Date of eligibility − Date of enrollment − Birth to Three program name	Percent of infants enrolled in EI by 6 months of age Percent of infants enrolled in EI who have date of entry reported to State EHDI Program	Amy Mirizzi, EHDI Coordinator / John Lamb, HPA2 CT Children's Medical Center audiologists CT Birth to Three Program Birth to Three hearing specialty program staff May be expanded to include: other CT diagnostic audiology center staff
Plan: Met with Quality Improvement Team, as part of CT EHDI Task Force meeting and identified area for improvement – a Birth to Three Program cannot begin delivering early intervention services to a child with hearing loss until the program obtains the diagnostic audiology evaluation report. There are barriers to timely receipt of diagnostic reports, which delays enrollment timeframes in some cases. Do: For the next five children pending enrollment, when a Birth to Three hearing specialty program director requests a diagnostic report from an audiology facility's medical records department, she will also notify the Audiology Manager and diagnosing audiologist, when identified, at that audiology center of her request. Study: The response timeframe will be documented and the QI stakeholder team will examine whether the audiology department's involvement in the process impacted outcomes. Act: A determination will be made whether additional protocol changes may have an impact. Once a successful strategy has been identified, opportunities for spread to the third hearing specialty B23 program and additional audiology centers will be explored and implemented piece-meal.				

Changes/Activities	**Timeline: Start Date – Estimated Completion Date**	**Outputs:** ***Process Measures***	***Outcome Measures***	**Lead Staff and Partner Support**
4.2 Identify change strategies aimed at educating parents about the EHDI process.	Year 1 – Year 3: September 1, 2014 – August 31, 2017	Develop parent resources aimed at expanding knowledge of EHDI process and providing family-to-family support resource information at the point of referral to early intervention. DPH sends monthly reports to Birth to Three on children newly diagnosed with hearing loss to confirm early intervention enrollment outcomes Birth to Three provides the following data fields: − Date of referral − Referral source − Eligibility status − Date of eligibility − Date of enrollment − Birth to Three program name	Families are linked to needed intervention and support services no later than age 6 months Percent of infants enrolled in EI by 6 months of age Percent of infants enrolled in EI who have date of entry reported to State EHDI Program	Ann Gionet, HPA Patti Silva, CT FSN/D-HoH Resource Coordinator CT Hands & Voices CT Birth to Three Program

Attachment 4: QI Team

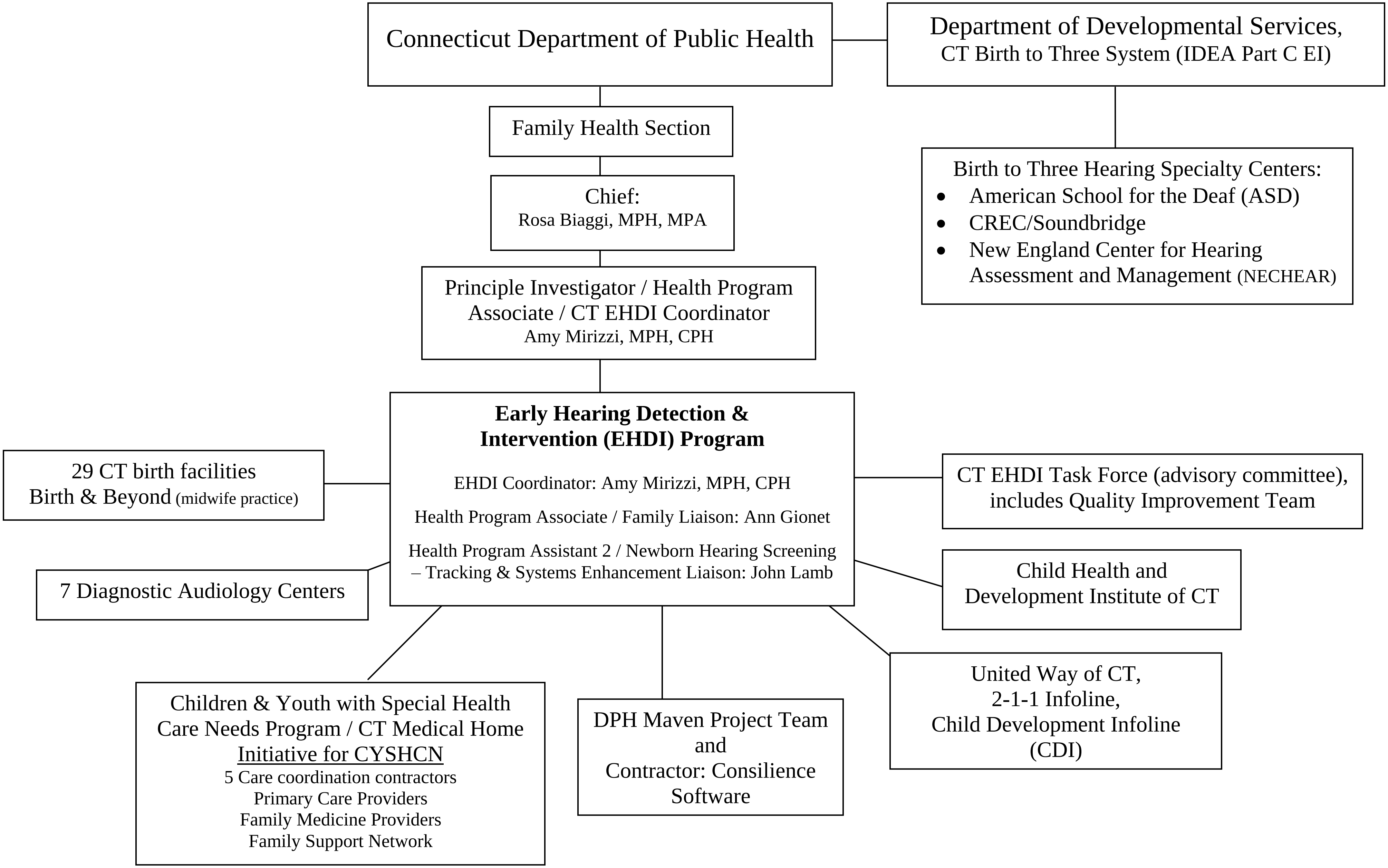
Connecticut Quality Improvement Team Members

Team Members Role	Name	Title	Organization Mailing Address
EHDI Coordinator	Amy Mirizzi	EHDI Coordinator, Health Program Associate	CT Department of Public Health 410 Capitol Avenue, MS # 11 MAT Hartford, CT 06134-0308
Data Point Person	John Lamb	Newborn Hearing Screening Tracking and Systems Enhancement Liaison, Health Program Assistant 2	CT Department of Public Health 410 Capitol Avenue, MS # 11 MAT Hartford, CT 06134-0308
State-level EHDI System	Ann Gionet	Family Liaison, Health Program Associate	CT Department of Public Health 410 Capitol Avenue, MS # 11 MAT Hartford, CT 06134-0308
Pediatric Audiologist	Nancy Bruno	Audiology Manager	CT Children’s Medical Center 282 Washington Street Hartford, CT 06106
	Carol Powell	Audiologist	Yale New Haven Hospital Yale Hearing and Balance Center 800 Howard Ave, 4th Floor New Haven, CT 06519
	Trisha Lake	Audiologist	Lawrence & Memorial at Waterford Outpatient Rehabilitation Services 40 Boston Post Road Waterford, CT 06385
	Terry Yanaway	Audiologist	University of Connecticut, Speech and Hearing Clinic 850 Bolton Road, Unit 1085 Storrs, CT 06269
EI System Representative/IDEA Part C	Eileen McMurrer	ChildFind Coordinator	CT Department of Developmental Services, CT Birth to Three System 460 Capitol Ave. Hartford, CT 06106-1308
Pediatric Audiologist / Early Intervention Program Representative	Kristin Vasil Dilaj	Audiologist AuD/PhD, CCC-A	New England Center for Hearing and Rehabilitation (NECHEAR) 354 Hartford Turnpike (Rte 6) Hampton, Connecticut 06247
		Assistant Professor in Residence	University of Connecticut, Department of Communication Sciences

Attachment 4: QI Team

Team Members Role	Name	Title	Organization Mailing Address
Early Intervention Program Representative	Elizabeth Cole	Director	CREC/Soundbridge 123 Progress Drive Wethersfield, CT 06109
	Carol Peltier	Assistant Principal	American School for the Deaf 139 North Main Street West Hartford, CT 06107
Deaf and Hard-of-Hearing Representatives / School for the Deaf	Jeff Bravin	Assistant Executive Director / Chief Operating Officer	American School for the Deaf 139 North Main Street West Hartford, CT 06107
	Fern Reisinger	Director of Outreach Services and Special Projects	American School for the Deaf 139 North Main Street West Hartford, CT 06107
AAP EHDI Chapter Champion	Brenda Balch	MD	AAP Chapter Champion
Parent Partner	Patti Silva	Chapter Coordinator D/HoH Outreach Coordinator, CT Family Support Network	CT Hands & Voices P.O. Box 210 Wethersfield, CT 06129-0210
	Terry Bedard, Esq.	President, Hear Here Hartford Chapter	Hearing Loss Association of America
ENT Doctor	Chris Grindle, MD	Otolaryngologist	CT Children's Medical Center Otolaryngology 282 Washington Street Hartford, CT 06106
	Scott Schoem, MD	Otolaryngologist; Division Chief, Otolaryngology	
Statewide Child Development Initiatives/Parent	Lisa Honigfeld, Ph.D.	Vice President for Health Initiatives	Child Health and Development Institute of CT (CHDI) 270 Farmington Avenue Farmington, CT 06032
Connecticut Deafblind Project	Karen Stockton	Audiologist, Consultant	Connecticut Deafblind Project 6 Arlington Heights Norwich, CT 06360

Attachment 5: Project Organizational Chart



Attachment 7: Summary Progress Report

Grant Years 1 – Grant Year 3, to-date: 9/1/2011 – 2/28/2014

Goal 1: Overall 99% of newborns born in a CT birth facility or to a CT resident at home will be screened for hearing loss by one month of age.

2012 CDC Data Report: 99% of infants born in CT were screened for hearing loss and 98.7% were screened before 1 month of age.

Objective: Work with CT midwife associations to investigate opportunities to expand partnerships with midwives performing home deliveries.

Results: Now that Maven: Newborn Screening System (NSS) records can be matched to Electronic Vital Records System (EVRS) records, the Maven: NSS automatically creates a new case for all infants with a birth certificate without a newborn screening match. This gives EHDI and other screening staff access to missing biographical records, including individual data on all home births, and facilitates tracking and follow-up activities aimed at ensuring EHDI staff are able to collect and report standardized, aggregated information on screening results for all occurrent births.

Objective: Sign the New England EHDI Border Babies agreement.

Results: On 9/17/2013, the Commissioner of the CT Department of Public Health joined the five other New England states and signed the Newborn Hearing Screening Interstate Exchange Agreement, which facilitates the sharing of newborn hearing screening results and demographic tracking information concerning residents of one state who were born in a different state among Newborn Hearing Screening Programs in the 6 New England States (and New York eventually). By gaining access to information about its residents CT will be able to provide appropriate and timely follow-up services and to maintain more accurate and complete information on newborn hearing screening results for its residents.

Goal 2: The percentage of newborns that receive follow-up after failure to pass newborn hearing screening will increase from 78% to 85% between Years 1 & 3 and those receiving follow-up by 3 months will increase from 57% to 62% over the same time period.

Objective: A CT EHDI Team will participate in the National Initiative for Children’s Healthcare Quality (NICHQ) Improving Hearing Screening and Intervention Systems (IHSIS) Learning Collaborative during the 2012-2013 Project Period.

Results: The following changes were tested during the IHSIS Learning Collaborative with the predicted result being: 1. Decreasing LTF/D; 2. Increasing the percent of infants diagnosed by 3 months of age; and 3. Increasing results reporting to the State EHDI Program.

1) Referrals given direct appointment with audiology – for all babies seen between April and August 2013, the team identified two birth hospitals to give any baby who referred his or her newborn hearing screening an appointment with an audiology center prior to discharge. The results at one facility demonstrated an improvement from 45% follow-up to 100% follow-up and

the average age at the time of completed follow-up improved from six weeks to three weeks. Efforts to spread this change are underway.

2) Infant referrals sent an informational pre-appointment letter – for the next 20 babies who receive an appointment for follow-up after failure to pass newborn hearing screening, the parents will be mailed a letter along with an appointment card providing: information about screening and importance of following up in a timely manner as well as instructions on how to best prepare the baby for testing. As predicted the audiology facility implementing this strategy experienced a decrease in the no show rate for appointments from 29% to 17%.

3) One audiology facility added the DPH EHDI Program's Diagnostic Audiology Reporting Form to their electronic report template for the diagnostic ABR. By streamlining the reporting process and providing a visual reminder, an increase in the timely and complete reporting of follow up results to the state EHDI was anticipated. Reporting percentiles increased from 50-60% to 84% during this PDSA cycle, and as a result the state team explored opportunities for spread. Two additional audiology centers implemented similar activities but modified to better fit their administrative structure. One facility added the scanned reporting form to their printable packet of materials and another facility added a reminder note at the bottom of their electronic health record form.

4) Birth to Three forms were modified to remind the three hearing specialty programs to obtain parental consent to share enrollment information on children with hearing loss with various professionals. Fields were added to the Birth to Three Form 3-3 to indicate permission for the following entities to communicate about the child: referring audiology site, DPH EHDI Program, pediatrician/family physician, and Birth to Three Program. It was predicted listing these professionals on the form would result in more providers requesting consent as well as an increase in parent consent, which would increase the ability to communicate and track early intervention enrollment numbers among children who are deaf or hard of hearing. DPH received an increased number of Birth to Three EHDI Forms during this testing cycle and 65% of these forms provided new diagnostic information the EHDI Program had not previously received. As a means of spread, all Birth to Three Programs were asked to obtain parental consent to share eligibility outcomes (enrolled/not enrolled) with primary care physicians.

Objectives: During the project period, the CT EHDI Program will contract with the Child Health and Development Institute of CT (CHDI) to examine the effect of "Just in Time Learning" (JITL) concepts that provide physician consultative EHDI support services to primary care providers (PCPs) caring for a child who is deaf or hard of hearing (D/HoH) on the provision of care. The Child Health and Development Institute (CHDI) will present the EHDI EPIC (Education Practices in the Community) module to at least 8 pediatric primary care offices each grant year to facilitate improved quality of care.

<u>Results:</u> DPH contracted with the CHDI to develop and implement an EPIC module on EHDI in collaboration with pediatric experts and other stakeholders. 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. Studies have shown that PCPs 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.

DPH, in collaboration with CHDI, continued working with CT's American Academy of Pediatrics (AAP) EHDI Chapter Champion, Dr. Brenda Balch, via a subcontract, to provide technical assistance and coaching services to PCPs addressing early identification of hearing loss and intervention to improve quality of care related to hearing loss among pediatric-age patients in the primary care setting. Dr. Balch worked closely with the DPH EHDI Program to design a protocol for support services that includes a telephone call from a consulting physician to the primary care provider of a newly identified baby who is D/HoH. The physician-to-physician consultation includes "just in time" educational materials to support access to care and linkages to the three statewide hearing specialty B23 Programs and the Family Support Network Deaf and Hard of Hearing Resource Coordinator as well as other needed resources. Dr. Balch also completes a summary form based on each case phone call outlining the progression of the conversation with the baby's PCP and what information was shared, based on a checklist of resources available, as well as providing open-ended feedback. EHDI staff use this data to analyze the intervention's impact on the timing of follow-up services. Project findings show an increase in the number of children referred to B23 after Dr. Balch contacts their PCP as well as evidence that the closer to the date of diagnosis Dr. Balch makes contact, the higher the referral percentage. Qualitative findings to date include: the majority of PCPs were aware that the infant had been diagnosed with hearing loss; PCPs were able to easily retrieve the newborn screening and initial diagnostic audiology results; PCPs had a more difficult time locating information regarding B23, subspecialty referrals and follow-up audiology evaluations; PCPs often believed further referrals after diagnosis would be made by others; PCPs were not aware of family support opportunities in the state; and PCP's were not aware of automatic eligibility criteria for B23.

Furthermore, this project was expanded to offer quality improvement Maintenance of Certification Part IV credits to participating physicians, which is now a requirement of their license. Dr. Balch contacts pediatricians of infants diagnosed with HL, via telephone, and offers coaching services and invites the PCP to participate in the quality improvement (QI) project for MOC Part IV credit. If the PCP participates, Dr. Balch will discuss the case with the PCP, mail a packet of materials, offer assistance, and help practices locate services and provide ongoing follow-up via phone, fax and/or email. The PCP requirements for MOC Part IV include: participating in QI education/training exercise; engaging in initial phone conversation with Dr. Balch regarding infant diagnosed with hearing loss; reviewing summary letter of phone conversation and all other resource materials; returning completed form to Dr. Balch regarding EI, subspecialty referrals and family support services offered; and submitting monthly data for each infant with hearing loss.

Goal 3: The CT EHDI Program will strengthen partnerships with other established early childhood programs to expand the current EHDI infrastructure in the state and to facilitate timely and appropriate audiological follow-up for infants who do not pass newborn hearing screening and early intervention for infants who are D/HoH.

Objective: The EHDI Program, in collaboration with B23, will renew data collection initiatives aimed at ensuring at least 85% of infants identified with an eligible hearing loss are enrolled in an EI program by six months of age (baseline and Year 1); increasing to 90% by Grant Year 3.
<u>Results:</u> The Memorandum of Understanding (MOA) between the DPH EHDI Program and the Department of Developmental Services – Birth to Three Program was revised and signed by both agency-heads in August 2013 in order to obtain parental consent at the time of enrollment to allow individual EI programs to release the names of children enrolled who have a diagnosis of hearing loss. Additionally Birth to Three shares enrollment outcomes for referred children with hearing loss when parent consent has been given.

Objective: The CT EHDI Program will promote family-professional partnerships within the CT EHDI system to ensure family-centered, culturally and linguistically competent care for all CT 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.
<u>Results:</u> EHDI staff support the regular participation of parents of children who are D/HoH in monthly EHDI Task Force meetings and facilitated National Center for Hearing Assessment and Management (NCHAM) parent stipend awards to support a CT parent in attending the 2012 and 2013 National EHDI Conference. The existing contract with CHDI was amended during the last reporting period to include working with the CT Family Support Network (FSN) to improve information availability and parent-to-parent support for families of children who are D/HoH. The FSN hired a Deaf and Hard of Hearing Resource Coordinator, Patti Silva, a parent of a child who is hearing impaired, who worked with a group of parents and professionals to successfully establish a CT Chapter of Hands & Voices (March 2012).

<u>Related Activities:</u>

The CT EHDI Program in collaboration with a planning committee that included CT Hands & Voices parents and representatives from the three hearing specialty B23 programs, planned and implemented a statewide full-day conference. The *CT EHDI Roadmap Conference: GPS Guiding Positive Supports for Families of Children with Hearing Loss – Navigating the Deaf and Hard of Hearing Experience* was held on May 8, 2013, in Cromwell, CT, and included guest speakers Dr. Karl White from NCHAM and Dr. Christine Yoshinaga-Itano, along with local parents and professionals who sat on the parent and professional panel discussion. Funding for this conference was made possible in part by the CDC Public Health Conference Support for Birth Defects and Developmental Disabilities grant. Approximately 100 attended, including 12 parents of children who are deaf or hard of hearing. In this working conference, participants learned about how their role fits into the national and state EHDI frameworks, as well as examined the sequence of experiences for families of children who are identified with hearing loss from screening through intervention. The post-conference evaluation yielded positive results.