PROGRAM NARRATIVE
INTRODUCTION

The New York State Department of Health (NYSDOH)/Health Research Incorporated (HRI) proposes to expand and elaborate on existing initiatives to further reduce the number of infants lost to documentation/follow-up after failure to pass newborn hearing screening with supplemental grant funding from HRSA. The current proposal will incorporate new methodologies to enhance the Newborn Hearing Screening Program's (NBHSP) efforts to support the linguistically and culturally diverse population in New York State (NYS). The NBHSP will continue to disseminate and advocate for the use of measures developed by HRSA through the National Initiative for Children's Healthcare Quality (NICHQ) learning collaborative that have proven effective in reducing loss to documentation/follow-up.

During 2007, in 144 NYSDOH-approved and regulated hospitals/birthing centers, there were 252,662 births, the third highest number of annual live births per state in the country. In 1999, NYS enacted statute mandating the administration of the NBHSP statewide, the only one of the largest three states to do so. This statute applies to all hospitals/birthing centers in NYS, regardless of their size or Neonatal Intensive Care Unit (NICU) status, creating screening rates in NYS that are higher than all other large states. Regulations requiring all hospitals and birthing centers in NYS to screen newborns for hearing loss were adopted in 2001 and more specifically addressed requirements for follow-up testing. Hospitals/birthing centers are required, as per 2001 regulations, to provide follow-up screening directly or through contractual agreement through other state-approved agencies to all such infants determined to have failed, or missed their initial screen. Based on screenings, referrals to local Early Intervention Programs (EIP) are required for all infants with a suspected hearing loss and for infants who fail their initial screen and for whom no follow-up hearing screening results were obtained. The NYSDOH has been the recipient of grant funding from HRSA since April 1, 2001 to support state activities related to the implementation of universal newborn hearing screening.

In NYS, newborn hearing screening is primarily the responsibility of hospitals/birthing centers which are required to administer the programs directly or by contract through other state-approved agencies. Regulations stipulate that hospitals/birthing centers are responsible for conducting infant hearing screening and carrying out follow-up screening or providing referrals to obtain follow-up screening on an outpatient basis to any infants who fail or do not receive screening prior to discharge from the facility. To facilitate this process all hospitals/birthing centers are required to designate an individual in charge of managing their hearing screening programs and to annually provide NYSDOH with updated contact information.

The NYSDOH also oversees the administration of services to infants and toddlers with disabilities in NYS, serving approximately 70,000 children annually. To meet local, state and federal data needs, and to assist with local and state management of early intervention services, the NYSDOH Bureau of Early Intervention (BEI) developed and maintains the Kids Integrated Data System (KIDS). KIDS also serves as the key data source used for state supervision and monitoring of the EIP at local levels.

All hospitals/birthing centers conducting newborn hearing screening are required to submit aggregate newborn hearing screening data to the NYSDOH on a quarterly basis. Required data elements include the number of infants screened, the number of infants who pass screening, the number of missed infants, and the number of infants referred for rescreening due to failed initial screening. The current data tool is formatted in Microsoft Excel and submitted to the NBHSP through an electronic mail log. This data tool has several limitations: It does not adequately record data for infants who were not discharged from the hospital due to prolonged stays in the NICU: It does not report the number of infants referred to the local EIP due to suspected hearing loss: It collects only aggregate data: It is not linked to the EIP KIDS data system for tracking of referrals; and data are submitted 90 days following the close of the quarter. In addition to addressing these issues, the current work on the development of a new data tool will expand on the required data elements collected and allow for the use of expanded information to increase culturally competent practices within the NBHSP. A data system is currently in development that will facilitate the collection of individual data, including demographics. This will enable the NBHSP to more carefully track and monitor follow-up for infants who fail the initial screening test and ensure a follow-up screen is performed or the child is referred to their local early intervention services. The collection of demographic data will also enable NBHSP staff to gain a broader view of the lost to documentation/follow-up population which will assist in efforts to tailor strategies culturally and linguistically to minimize the loss as necessary.

In an effort to increase the diversity of data reported through the NBHSP, the process of revising regulations to allow for the collection of individual level data has begun. This new data system will allow for the gathering of demographic information, strengthening the NBHSP's ability to develop and employ changes that are tailored to address the sensitive and diverse cultural issues that impact loss to documentation/follow-up. In addition, the collection of individualized data will significantly enhance the NBHSP's ability to track, monitor and follow-up with families of infants who have failed, or missed their initial screen, reducing the amount of infants who are lost to documentation/follow-up. NYSDOH is currently in the process of examining a memorandum of understanding (MOU) that has been developed for several New England states to be able to share information on babies that are born in NYS and reside in a bordering state or for those infants that are transferred to a NYS hospital prior to discharge. This MOU will function to increase the follow-up of babies that are lost to follow-up in the current system.

Grant funding is received from the U.S. Department of Education, the collaborative effort between the statewide Early Intervention Program (EIP) and hospitals/birthing centers. This includes local EIP administration in the application of the NBHSP at the local level. Referrals to the EIP in an infant's county of residence can take place at two main junctures in the newborn hearing screening process:

- If an infant who has failed their initial hearing screening does not receive a follow-up screening within 75 days post-discharge, the facility responsible for reporting data to the NYSDOH (usually the birth facility) may refer the family to the local EIP to facilitate the follow-up visit for the second hearing screening.
- After an infant fails two hearing screenings, they may be referred to the local EIP for a confirmatory (diagnostic) hearing test.

Using data received from hospitals, the NYSDOH provides each designated hospitals/birthing center's Newborn Hearing Screening Program manager with an annual summary performance report. This performance report assists program managers with determining the need to initiate changes, consistent with screening regulations, to increase their quality assurance efforts. The report includes individual facility and statewide data for certain key indicators including: infants screened for hearing loss prior to hospital discharge; infants screened for hearing loss between birth and one month; infants who failed the initial screening; infants who returned post-discharge for a rescreen; and families who refused screening.

To assist in maintaining statewide newborn hearing screening in a manner consistent with NYS Public Health Law and regulations, the NYSDOH conducts conference calls with hospitals/birthing centers to improve compliance with screening regulations. This has enabled NYSDOH to identify several barriers that prevent some hospitals/birthing centers from reducing the number of infants lost to documentation/follow-up, including staff shortages, equipment failure, tracking and monitoring of infants lost to follow-up. Often hospitals have inadequate protocols for referral of infants with suspected hearing loss to their local EIP.

In April 2008, NYS was chosen to participate in the 2008-09 National Initiative for Child Healthcare Quality (NICHQ) learning collaborative. During this collaborative, New York and eight other states tested small measures of change through Plan, Do, Study, Act (PDSA) cycles. These cycles were directed at improving the follow-up rates with one New York City (NYC) hospital, Montefiore Medical Center in the Bronx. Cycles tested included the following: collecting a second point of contact and primary care provider information for infants who failed the initial screen, conducting a survey of parents of children with hearing loss, improving the EI referral process intake in NYC, using the Citywide Immunization Registry (CIR) to locate infants who did not comeback for rescreens, creation of faxback forms to primary care providers (PCPs) with hearing screening results, surveys of parents at Montefiore to determine why parents do not return for rescreens, and exploring the widespread use of rotating PCPs or clinic physicians by the Montefiore population. The improvement of EI referral intake procedures, use of the CIR to locate children, and the parent survey provided valuable information to NYC EIP and Montefiore Hospital NBHS staff. Other PDSAs provided information that would help shape statewide quality improvement strategies.

The proposed project will utilize lessons learned from previous initiatives and build on them in order to continue to specifically address program barriers in NYS that contribute to loss to documentation/follow-up for our infants and families.

PROGRAM NARRATIVE
NEEDS ASSESSMENT

NYS is one of the most racially and culturally diverse states in the nation. Data from vital statistics indicate that of the 252,662 live births in 2007, 164,555 (65.1%) were reported as Caucasian; 52,450 (20.8%) were Black; and 35,324 (14%) were other. In 2007, 0.6% of births in NYS occurred out of a hospital. Of all live births, 60,326 (23.9%) were reported with a Hispanic ethnicity. This may reflect an increase in the Hispanic population, as the 2000 census shows that 15.1% of people identified themselves as Hispanic. The counties having the largest source of immigrants in NYC are the Dominican Republic, China, Jamaica, Guyana, Mexico, Ecuador, Haiti, Trinidad and Tobago, Colombia, and Russia.[1] Half of these are Spanish speaking nations. In addition, approximately 170 languages are spoken in NYC.[2] In several hospitals/birthing centers with predominantly Spanish speaking maternity staff, there are language barriers as the Newborn Hearing Screening Program (NBHSP) does not have bilingual staff.

NYS has the third highest number of annual live births per state in the country. In addition to the challenges surrounding the diverse population, there are also challenges to be met due to the large volume of births. Twelve facilities in NYS have over 4,000 annual births, and the largest approaches 7,000 annual births. The statewide average for a hospital/birthing center is over 1,600 births and the median is over 1,400 births. Therefore, the implementation of strategies learned through the NICHQ learning collaborative may prove to be difficult due to limited staff and resources. Current staff continues to engage in daily activities such as technical assistance for data reporting/ facility protocols, development of a new data system, and training new Newborn Hearing Screening (NBHS) Managers and other hospital staff. Additional funds and staff are necessary to develop and implement quality improvement activities, develop training materials, conduct trainings, and provide onsite quality assurance visits. Onsite visits are vital in building a collaborative partnership to decrease the percentage of children lost to documentation/follow-up.

The NYSDOH maintains a statewide database as part of its oversight of Newborn Hearing Screening Programs. Aggregate data has been collected from hospitals since the NYS newborn hearing screening regulations were implemented. Calendar year 2002 was the first full year of

[1] "The Newest New Yorkers, 2000". New York City Department of City Planning. 2004. http://home2.nyc.gov/html/dcp/html/census/nny_exec_sum.shtml. Retrieved on 2008-05-27. "The Dominican Republic was the largest source of the foreign-born, numbering 369,200 or 13 percent of the total, followed by China (262,600), Jamaica (178,900), Guyana (130,600), and Mexico (122,600). Ecuador, Haiti, Trinidad and Tobago, Colombia, and Russia rounded out the city's ten largest sources of the foreign-born."

[2] "Queens: Economic Development and the State of the Borough Economy" (PDF). New York State Office of the State Comptroller. June 2006. http://www.osc.state.ny.us/osdc/rpt3-2007queens.pdf. Retrieved on 2008-09-01.

data submitted to the NYSDOH. In 2002, 96.9% of infants born in a hospital/birthing center were reported to be screened for hearing loss prior to discharge or before one month of age. This reported screening rate has increased to 99.3% in 2007. The percentage of infants who failed to pass the birth admission screening was 4.8% in 2002 and decreased slightly to 3.8% of screenings in 2007. NBHSP staff are exploring what may have caused this decrease. Efforts to ensure that follow-up testing occurs for these infants with suspected hearing loss is a top priority, since the goal of screening newborns for hearing loss is to identify those with hearing loss as early in life as possible, and link them and their families to appropriate Early Intervention (EI) services. Follow-up rates for infants in NYS who failed to pass their birth admission screen were 72.9% in 2002. This has increased to 77.4% in 2007. Of the 144 hospitals/birthing centers in NYS, approximately 50 outlier hospitals have lost to documentation/follow-up rates below the statewide average of 77.4%.

To better assist outlier hospitals, the NYSDOH conducts technical assistance calls with hospitals/birthing centers that do not meet certain screening and follow-up screening standards set by the Joint Committee on Infant Hearing (JCIH). Through these calls, the NYSDOH assists hospitals in reviewing and revising existing protocols for universal newborn hearing screening. The following factors have been found to result in improved follow-up rescreen rates: providing education to parents on the importance of follow-up for infants that fail, maintaining direct relationships with pediatricians and conducting follow-up testing within the hospital/birthing center's own facility rather than referring out. In addition, it has been stated during conversations with both NBHS managers and parents that some hospital staff and/or primary care providers have dismissed parental concerns over failed initial screens due to the high false positive rate. Based on a small scale survey through the NICHQ learning collaborative administered to parents of infants with a hearing loss, 80% indicated that they were not given educational materials prior to discharge from the hospital and 80% reported that their infant's pediatrician did not have the results of the hearing screening at the first well-child visit. Therefore, parent and provider education is a key factor in facilitating follow-up. Due to the findings, the NBHSP will develop a quality assurance protocol that will be used in the future during site visits to hospitals and birthing centers to assess facility compliance with NYS statute, regulations and JCIH benchmarks. Additional materials that are culturally and linguistically sensitive to the NYS population of families will be developed for use in training of newborn hearing screening staff as well as with families directly.

Data are accessed from the statewide Early Intervention Program (EIP) to determine whether the implementation of statewide newborn hearing screening has had an impact on earlier referrals to the EIP and EI services delivered to young children with hearing loss and their families. During the 2000-01 program year, which was prior to the implementation of newborn hearing screening, only 20% of children with hearing loss were referred to the EIP during the first three months of life, and 42% were referred by six months of age. Since the implementation of statewide newborn hearing screening in the fall of 2001, the mean age at identification for children with hearing loss in the EIP has decreased from 14 months to 8 months, and the median age at referral has decreased from 12.7 months to 4.1 months of age.

Due to limitations in collecting only aggregate data, the NYSDOH is limited in its ability to generate data for certain reporting requirements. In addition, the NBHSP data tool does not have

a link with important related information such as referral to EIP, immunization registry, and audiological diagnosis. As reported by hospitals, the number of infants who were lost to documentation/follow-up in 2007: 1) 1,919 infants between hospital and outpatient screening (number of infants who missed their hearing screening and outpatient screening was not reported back to the birthing facility); 2) 7,431 infants between outpatient rescreening and initial hospital screening; 3) rescreening and audiological diagnosis—this number cannot be estimated because the results of non-EIP diagnostic evaluations are not collected in either the NBHS or EIP data system; and, 4) 987 infants between diagnosis and entry into early intervention. These data are an underestimate since families may obtain follow-up testing through other health care providers other than the EIP. Such follow-up services and audiological evaluations for children are not reported to the NYSDOH. Also, documentation of diagnoses in the KIDS system only allow for two ICD codes. Therefore children with multiple conditions including hearing loss may be under counted. The new NBHS data collection system being developed will provide more accurate data.

Newborn hearing screening technical assistance calls, received from program managers from the 144 hospitals and birthing centers across NYS, indicate that their staff turnover requires ongoing training and technical assistance, both in the area of data collection/input and submission to the NYSDOH, in order to enhance the provision of follow-up care. Challenges faced in providing follow-up services include: lack of insurance coverage, difficulty finding families after hospital discharge, lack of information about the steps to take after newborn hearing screening to diagnostic audiological evaluation, and difficulty accessing audiology providers.

There appear to be adequate numbers of licensed audiologists in NYS. Currently, there are 12,291 licensed audiologists in NYS. Of these, 425 audiologists are approved by the NYSDOH to provide audiological services to children in the EIP. Those 425 audiologists have pediatric experience. NBHSP is currently exploring which of the remaining licensed audiologists (11,896) that provide services to the pediatric population could become approved Early Intervention Providers. In addition, there are capacity issues in rural areas of the state.

Anecdotal information obtained in technical assistance calls from parents of young children with newly identified hearing loss suggest that parents need more information and materials about the newborn hearing screening process. In addition, parents and early intervention providers seek information through requests for technical assistance and training concerning intervention services, technology choices, and options for communication with children identified with a hearing loss. Currently, NBHS staff are having discussions with parents regarding a Hands and Voices' Chapter in NYS. In addition, the NBHSP has started to post NBHS information for parents and others on the NYSDOH's Web site.

PROGRAM NARRATIVE
METHODOLOGY

The NYSDOH will initiate additional activities that will focus on improving measurable outcomes for infants with hearing loss and their families by improving appropriate and timely follow-up. The focus area will be the time period between initial hospital screening and rescreening. As previously mentioned in the Needs Assessment section, this is an area that requires improvement through a more strategic and consistent process. The NYSDOH proposes to reduce infants lost to documentation/follow-up between the initial hospital screening and post discharge rescreening from 22.6% to 5% in the next three years, as measured by data submitted directly from hospitals/birthing centers. In addition, the NBHSP proposes to increase the cultural competency of staff provider services to families. The NBHSP plans to accomplish this goal by carrying out specific targeted initiatives. Initiatives will include developing a parent friendly script for delivery to parents of an infant with a failed initial screen, producing and delivering training to expand cultural competency of front line healthcare personnel performing screening, producing and disseminating new culturally sensitive materials to hospitals/birthing centers on the NBHSP and referral to Early Intervention (EI), implementing a NBHS protocol in all hospitals/birthing centers statewide, providing individualized technical assistance and onsite visits to hospitals/birthing centers specifically targeting hospitals with the highest lost to documentation/follow-up rates, and evaluating and disseminating findings from the project.

The NYSDOH Early Hearing Detection and Intervention (EHDI) coordinator and Newborn Hearing Screening (NBHS) Program Manager will recruit and hire a Spanish speaking Public Health Representative (or similar position) as a NBHS statewide Follow-up Coordinator. This staff person will be responsible to work directly with birthing hospitals including the hospitals' front line staff that includes NBHS screener(s), NBHS manager and discharge nurse(s) on lost to documentation/follow-up activities between initial hospital screening and rescreening. The Follow-up Coordinator will participate in technical assistance conference calls and onsite quality assurance visits with hospitals that did not meet the NBHSP's quality targets. The targets include two identified Joint JCIH benchmarks for which hospitals report aggregate data to the NYSDOH. The two JCIH benchmarks are: (1) 95% of infants are screened birth to one-month, and, (2) 70% of infants return for post discharge rescreen due to a failed initial screen. The bilingual capability of the Follow-up Coordinator will assist him/her in creating curriculums and trainings that are adaptable to multiple different cultural interpretations. The Follow-up Coordinator will also develop curriculums and written materials in and review translations of already created materials in Spanish which accounts for 13.6 % of the 4,962,921 residents of NYS (28%) who speak a language other than English.

The Follow-up Coordinator, in conjunction with other NBHS staff and additional NYSDOH staff who have knowledge and expertise in cultural and linguistic competencies, will develop training materials that can be used in various presentation modes including web-based and face- to-face training. The training materials will address the cultural richness and diversity of populations served. The NBHSP will consult with the NYSDOH Office of Minority Health on the development of training curriculum.

Production of a training DVD/video for NBHS screeners is planned. This DVD/video will describe the basic NBHS process for screeners, including descriptions of equipment used, how to deliver the screener script properly, how to discuss referral to Early Intervention Program (EIP), what to do for infants missed prior to discharge, what to do for infants who fail the initial screen, and how to properly administer follow-up activities. This DVD /video will be marketed to hospitals/birthing centers as a training tool for their screeners and other front line staff. The DVD/video will be equipped with both English and Spanish subtitles to facilitate viewing by the widest audience possible. Also, online self-paced learning tutorials will be developed. These tutorials will be short in duration (15 minutes or less) to enhance viewability and be consistent with online learning principles. The tutorials will address specific NBHS initiatives or emerging challenges. The first planned tutorial will address the delivery of a screener script in a culturally competent manner. This will include an explanation of how culture affects one's view of health care and healthcare priorities. The concept of cultural relativism will be introduced to screeners along with examples of how culture affects one's world view of illness and healing, and explanation of how these concepts affect a parent's healthcare decision-making. The second tutorial will focus on the use of language and wording that may enhance a parent's understanding of the serious effects of hearing loss and the importance of follow-up. The third tutorial will address language barriers and outline several strategies to address such barriers. Examples of additional planned tutorials include culturally competent discussions with parents regarding what a referral to EIP is, how to make referrals to EIP (based on regions), strategies for collecting additional contact information, reducing median follow-up appointment times, adapted National Center for Hearing Assessment and Management (NCHAM) recommendations regarding privacy issues, and how to use the NBHS data module (after it is developed). The planned tutorials will provide a foundation on which to continue to expand with additional tutorials used to address ongoing issues in the NBHSP. These tutorials will be produced with Adobe Captivate software and would be accessed through the NYS Health Commerce Network, a secure department intranet site for NYS healthcare providers. The tutorials will have assessments built in and be tracked through a learning management system so that screener competency can be tracked. Hospitals with low screener scores will be contacted and technical assistance provided. If competency does not improve, more intensive onsite support and training may be required.

The NYSDOH has experience in developing best practices including the issuance of a series of clinical practice guidelines (CPG) on several topics and as part of its mission to make a positive contribution to the quality of care for children with disabilities. The 2007 CPG on *Hearing Loss* provides guidelines to parents, clinicians and others based on recommendations of a multidisciplinary panel of experts composed of both clinicians and educators, and parents. The panel developed the guidelines using available scientific evidence on "best practices" for the assessment and intervention for young children from birth to age three with hearing loss.

The Agency for Healthcare Research and Quality (AHRQ) established the methodology for the development of the CPGs. The AHRQ "methodology was used because it is an effective, scientific, and well-tested approach to guideline development." Scientific studies that met preset criteria for adequate evidence were thoroughly reviewed by the panel and the results were abstracted onto evidence tables. The CPGs have been disseminated through:

a. The BEI Web page on the NYSDOH Web site. (http://www.nyhealth.gov/community/infants_children/early_intervention/)

b. The Department's intranet news and Wadsworth Library. The New York State Library System also has hard copies and makes the guidelines available throughout the state.
c. BEI training contractors to more than 800 trainees attending workshop sessions.
d. E-mails to Early Intervention Officials and Early Intervention Managers at county offices, interested parties, e.g. large provider advocates/groups, announcing the availability of the CPGs including the Web site address for locating the CPGs on the NYSDOH-BEI Web page.
e. Distribution to all panel members.

In addition, the Bureau of Early Intervention (BEI) sent letters to individual physicians, group practices and other individuals announcing the availability of the Hearing Loss guidelines. Requests from local organizations, state agencies, early childhood development groups, associations, and colleges/universities from many states and even other countries to reprint sections and/or chapters of the guidelines are frequently received.

The guidelines have been issued in three book versions with each having different levels of detail describing the literature review methods and the evidence supporting the recommendations. Additional CPGs have been developed and disseminated for Autism/Pervasive Development Disorders (1999), Communication Disorders (1999), Down syndrome (2006), Motor Disorders (2006), Hearing Loss (2007) and Vision Impairment (2008). Compact discs consisting of all versions for the four most recent titles are available.

The Bureau of Early Intervention is in the process of translating into Spanish the CPG quick reference guides that include the Hearing Loss guideline.

The Follow-up Coordinator, in conjunction with other NBHS staff, identified NBHS hospital staff and identified parents from diverse cultural backgrounds, will develop a parent friendly script for translation into seven languages that hospital staff can use to highlight the importance of follow-up steps and to motivate families in conducting follow-up activities regarding their infant's inpatient failed screening. This script will be disseminated to hospital staff through training and technical assistance.

The Follow-up Coordinator, in conjunction with other NBHS staff and parents, will develop a family roadmap that will be provided to parents and explained by hospital staff when the infant does not pass the initial screening prior to discharge. The roadmap will include information on what the next steps are for parents to follow. A promotional item (e.g., pen), with newborn hearing screening information and a phone number, will be provided with the roadmap to remind parents of the importance of the rescreen. The roadmap will provide clear, specific instructions on what happens next through a visual format. The roadmap will be modeled after Colorado's Infant Hearing Program- *A Roadmap for Families*. The roadmap will include what follow-up activities need to be conducted at birth, before 1 month, before 3 months, and before 6 months. The NBHSP will print and distribute the roadmap to hospitals. In addition, the Follow-up Coordinator will provide training via conference calls to all hospitals on how the hospital should use this roadmap with parents.

During the NICHQ collaborative and with ongoing communication with hospitals, it was revealed that NBHS results were not always included in the infant's information that is sent to

the primary care provider (PCP) /medical home. Some hospitals have a standardized process and other hospitals do not. The Follow-up Coordinator, in conjunction with other NYSDOH and NBHS staff and parents, will develop a template letter that hospitals can send to the PCP/medical home regarding the results of the infant's hearing screen. The Follow-up Coordinator will work with selected hospitals that currently do not report the infant's newborn hearing screening results to the PCP/medical home. Many NBHS screeners/managers do not capture the infant's PCP/medical home at time of discharge for follow-up activities when conducting the infant's second screening. In addition, when exploring how to obtain unduplicated, identifiable, individual newborn hearing screening data; the NBHSP discovered that the NYSDOH Statewide Perinatal Data System (SPDS) also does not capture an infant's PCP/medical home. The SPDS is a statewide database that maintains a record of all live births within NYS. The NBHS Program, in conjunction with our Division of Family Health, has submitted a "change request" to have this field added in addition to other newborn hearing screening data fields. The Follow-up Coordinator will work with hospitals on how they will now be able find the infant's PCP/medical home information.

To determine timely access to diagnostic testing and possible reduction of lost to documentation/follow-up, the NBHSP will participate in a NCHAM survey of pediatric audiology centers. NCHAM will analyze the survey results and provide a summary of the results for NYSDOH. As previously stated in the Needs Assessment section, NYSDOH is exploring how many of the 12,291 licensed audiologists in NYS provide services to the pediatric population. These results will provide the NBHSP with further descriptive information on diagnostic hearing assessment methodologies that may lead to better infant diagnostic practices.

The Follow-up Coordinator, in conjunction with other NBHS staff, will develop and disseminate a newborn hearing screening information letter to NYS OB/GYN offices/clinics on how they can order, free of charge, the NBHS brochure *Can Your Baby Hear You – Information for Parents.* This brochure describes the importance of the hearing screening test, indicates the causes of hearing loss and lists the developmental milestones that parents should be aware of. The letter will include a small supply of the brochures and an order form.

The Follow-up Coordinator and other NBHS staff will work with the American Academy of Pediatrics Chapter Champions within NYS (Upstate, Long Island, and Greater NYC Area) to submit an article on the importance of newborn hearing screening to include in the various regional newsletters and post on their Web sites. In addition, staff will explore providing NBHS information to family practitioners via the American Academy of Family Physicians.

The Follow-up Coordinator and other NBHS staff will develop a NBHS DVD/video public service announcement that hospitals and PCP/medical homes would show to parents within hospitals rooms and physician/clinic waiting rooms. This DVD/video will describe the basic NBHS process from a parent perspective, including descriptions of equipment used and how they work, what the referral to Early Intervention Program is and what it means for families, the importance of obtaining follow-up screens for infants that fail or are missed, how to use the NYS NBHS Family Roadmap, and how intervention at an early age effects speech and learning outcomes. This DVD/video may highlight a parent with a child with a confirmed hearing loss or include an interview with a parent so that personal experiences can be shared. This will

maximize the impact on parents by demonstrating through a real-life example the importance of follow-up on a child's development. The DVD/video will be equipped with both English subtitles for the hearing impaired population as well as Spanish subtitles (possibly other languages depending on level of need) to facilitate viewing by the widest audience possible.

PROGRAM NARRATIVE
WORK PLAN

Objectives	Activities	Timeline	Responsible Staff	Performance Indicators
1. Hire a Follow-up Coordinator	1. Advertise/Recruit for the position.	9/15/2009	Brenda Knudson Chouffi/Candace Adams Grossjohann	Follow-up Coordinator joins NBHS staff by late October.
2. Reduce infants lost to follow-up between initial hospital screening and post discharge re-screening from 22.6% to 5% within 3 years.	1. Develop a parent friendly script for delivery to parents of an infant with a failed screen.	12/1/2009	NBHSP Staff	Script completed.
	2. Create a tutorial addressing script delivery in a culturally competent manner.	2/1/2010	Follow-up Coordinator/NBHSP Staff	Module created and posted to internet.
	3. Develop and disseminate a family roadmap to direct next steps of action for parents of an infant who failed NBHS.	4/1/2010	Follow-up Coordinator /NBHSP Staff	Roadmap created and disseminated.
	4. Create 2nd tutorial addressing the use of language and wording regarding importance of NBHS and follow-up.	6/1/2010	Follow-up Coordinator /NBHSP Staff	Module created and posted to internet.

	5. Create a 3rd tutorial addressing the language barriers in communicating with parents of infant who fail NBHS.	8/1/2010	Follow-up Coordinator /NBHSP Staff	Module created and posted to internet.
	6. Develop face-to-face training curricula and implement in hospitals/birthing centers	11/1/2010	Follow-up Coordinator/ NBHSP Staff	Trainings developed and provided to hospitals/birthing centers.
	7. Identification and onsite visit of hospitals/birthing centers identified as having low performance scores on post-training assessments.	4/1/2011	Follow-up Coordinator /NBHSP Staff	Onsite visits completed and additional education provided.
	8. DVD/Video for NBHS screeners developed and marketed to hospitals/birthing centers.	7/1/2011	Follow-up Coordinator /NBHSP Staff	DVD/Video produced and distributed to hospitals/birthing centers.
	9. Implement a revised Newborn Hearing Screening protocol in all hospitals/birthing centers statewide, as needed.	11/1/2011	Candace Adams Grossjohann/ Follow-up Coordinator /NBHSP Staff	Training on revised protocols delivered and survey results indicate protocol is effective.
	10. Provide individualized technical assistance to hospitals/birthing centers specifically targeting hospitals with the highest loss to documentation/follow-up rates.	Ongoing	Candace Adams Grossjohann/ Follow-up Coordinator /NBHSP Staff	On-site visits completed and protocols revised.

	11. Evaluate and disseminate findings from the project.	9/1/2012	Brenda Knudson Chouffi/Candace Adams Grossjohann	Findings disseminated.
3. Improve communication between service providers and hospitals/birthing centers	1. Add data fields to the State Perinatal Data System (SPDS) identifying the PCP medical home to facilitate hospital communication.	3/1/2010	Brenda Knudson Chouffi/Candace Adams Grossjohann	Medical home information collected in SPDS booklet.
	2. Develop a template letter hospitals can forward to PCPs/medical home advising them of the results of the infant's hearing screening	6/1/2011	Follow-up Coordinator /NBHSP Staff	Letter developed and disseminated to hospitals/birthing centers.
4. Increase awareness of importance and objectives of hearing screening	1. Develop a letter to New York State OB/GYN offices and clinics regarding the newborn hearing screening process with information on how they may obtain the general NBHS brochure to provide to their patients.	6/1/2011	Candace Adams Grossjohann/ Follow-up Coordinator	Letter developed disseminated to NYS OB/GYN offices and clinics.
	2. Work with NYS American Academy of Pediatrics Chapter Champions to produce an article on the importance of NBHS to be included in regional newsletters and Web sites.	3/1/2012	Brenda Knudson Chouffi/Candace Adams Grossjohann	Article written and published.

	3. Develop a public announcement for hospitals and PCPs/medical homes to show to parents.	9/1/2012	Follow-up Coordinator /NBHSP Staff	Announcement produced and disseminated to hospitals/birthing centers and PCPs/medical homes for use.

PROGRAM NARRATIVE
RESOLUTION OF CHALLENGES

This project proposes to hire a full time Follow-up Coordinator who will be responsible for developing and implementing training, technical assistance, and quality assurance measures for NYS hospitals and birthing centers. The addition of a Follow-up Coordinator will enable the NBHSP to more closely align practices across NYS and facilitate consistency and high quality service delivery for families. The large geographic area of NYS and the large number of hospitals/birthing centers pose a considerable challenge for the provision of quality monitoring within the NBHSP. It would be cost prohibitive and logistically impossible for the NBHSP to perform follow-up at the individual family level. Rather, this project proposes that the Follow-up Coordinator design a comprehensive training and technical assistance curriculum that would be provided to all hospitals/birthing centers. The training and assistance provided will be tailored to address the varying needs of the hospitals/birthing centers, creating an individualized approach to each set of challenges the hospital/birthing centers face. For all hospitals/birthing centers, training and ongoing support will be geared toward front line hospital/birthing center staff within the NBHSP. These staff includes the hospitals' NBHS screener(s), NBHS Manager and discharge nurse(s). Training and support will focus on activities to decrease the lost to documentation/follow-up rate between the initial screen and a second screen for those babies that require it. As a part of the NBHSP's annual evaluation of facilities performance in newborn hearing screening, those hospitals/birthing centers that are identified as requiring significant support due to their failing several quality standards will be prioritized for an onsite, quality assurance visit including face-to-face training by the Follow-up Coordinator. The Follow-up Coordinator will develop training curriculums which will be customized as hospitals/birthing centers are identified as needing support, to assist in lowering their loss to documentation/follow-up rates. These face-to-face trainings can be provided in the form of a workshop or multiple sessions depending on the needs of the individual hospital/birthing center. For the remainder of the hospital/birthing center throughout the state, conference calls and technical assistance will be tailored to their individual support needs.

In addition to onsite visits, face-to-face trainings and conference calls, the Follow-up Coordinator will develop, in conjunction with other NBHS staff, web-based training modules that will be available to all facilities in NYS as well as families and medical home participants (i.e., primary care physicians, pediatricians, obstetricians). The web-based training modules will include a highlight of the NYS regulations and provide strategies for implementing high quality newborn hearing screening programs at the community level.

The diverse population in NYS presents unique challenges for culturally and linguistically competent initiatives as previously described. In an effort to provide quality care to families by the NBHSP, our proposed activities will address the language and cultural needs of NYS's diverse population. Program staff will recruit and hire a bilingual Follow-up Coordinator in order to help address language diversity within the state. In addition, written materials developed for the project will be translated into seven different languages that are the primary languages spoken within NYS (English, Spanish, French, Chinese, Russian, Bengali, and Urdu) as well as developed according to a specific literacy level. In a further effort to develop culturally competent providers within the NBHSP, the Follow-up Coordinator will provide

support and training to front line facility staff. Training objectives will include increasing awareness of multicultural health issues and engaging the vast variety of individuals and families involved in newborn screening. In addition to the challenges surrounding the diverse population, there are also challenges to be met due to the large volume of births (third largest in the nation). Implementation of strategies identified as a result of the NICHQ learning collaborative will be difficult to implement statewide without additional staff and resources provided through the supplemental funding opportunity.

PROGRAM NARRATIVE
EVALUATION AND TECHNICAL SUPPORT CAPACITY

The proposed strategies, protocols and work plan activities will be measured through process and impact evaluation that include: change in data reported by hospitals; onsite visits to the targeted hospitals/birthing centers to review usage of the strategies; tracking the number of hospitals/birthing centers adopting the proposed practices; observing the change in number of hospital/birthing center's reporting NBHS results to the primary care provider (PCP)/medical home through consistent use of pre-developed script; tracking of usage of training materials by hospitals and incorporation into current practices; monitoring of competency of culturally diverse training tutorials through the use of learning management system; pre and post assessments of changes in follow-up following dissemination of parent friendly scripts to hospitals; changes in baselines associated with distribution of written materials including the family roadmap; and observing the change in performance of hospitals/birthing centers through pre-post measures and changes in established baselines.

The quarterly newborn hearing screening data tool is used by hospitals and tracks follow-up screenings. The increased frequency of data reviews will enable NBHSP staff to track the success of the implemented changes in a more efficient manner. The collection of these data will provide information on the trends in lost to documentation/follow-up and can be used to evaluate strategies outlined in the work plan. Since this same data tool has been utilized prior to the implementation of the new follow-up strategies, baseline data can be used for comparison of data following implementation.

The Early Intervention data system, KIDS, is already in use to compare rates for referral to the EIP for evaluation and services prior to and following implementation of NBHS follow-up strategies and can continue to effectively track referrals following implementation of these additional NBHS strategies. Data will be generated based on various time periods and also allow stratification by regions/county.

Onsite visits to targeted hospitals regarding these additional NBHS strategies will take place during the first year. During onsite visits, medical records and tracking systems will be reviewed and actual screening procedures will be observed by NBHSP staff. Interactions between hospital front line staff, who deliver the scripted narrative and written materials, and parents will be observed to further evaluate cultural sensitivity and effectiveness. This additional interaction between hospitals/birthing centers and the NBHSP will provide feedback to hospitals/birthing centers on data reported. This will also enable NBHSP staff to observe direct implementation of additional strategies and identify hospitals/birthing centers competency in addressing the diverse linguistic and cultural differences in NYS. Noted trends, anomalies, and outliers of reported data will be discussed with selected hospitals/birthing centers during and after onsite visits, via conference calls and ongoing technical assistance. In addition, the Follow-up Coordinator will provide training and technical assistance to facility staff regarding the new strategies.

Currently the NBHSP is in the process of developing and implementing a pre-assessment questionnaire which will be completed by each hospital/birthing center. The questions are tailored to explore current screening protocol, staffing plan and referral procedures. Once the

protocol is instituted, a similar assessment will be administered to assist in tracking the success of the work plan strategies. The NBHSP will work closely with the three NYS American Academy of Pediatrics Early Hearing Detection and Intervention District Chapter Champions to roll out the protocol across NYS. The Chapter Champions will encourage and support their assigned regional hospitals to implement the NBHS protocol.

The NYSDOH will analyze individual hospital summary data reports submitted by the 144 NBHS facilities to evaluate the project strategies identified in the Methodology section of this proposal. The following key indicators will be used: 1) percent of infants screened birth to 1 month (i.e., how many children are screened), 2) percent failed birth admission screening (i.e., how many children are being identified with potential hearing problems as a result of the initial screening), and 3) percent returned post-discharge rescreen (i.e., how well are children being followed up, when needed). Follow-up on trends, anomalies and outliers, indentified by trend analysis over time and comparisons between hospitals/birthing centers, will help detect data errors, events that have a one-time impact on the system and the longer term effects of new policies/approaches. Preferably, this follow-up will identify best practice strategies and solutions to specific problems that may occur. These best practices and solutions would then be disseminated to other hospitals/birthing centers to further decrease the loss to documentation/follow-up.

The NYSDOH also provides technical assistance through individual telephone contacts, and through conference calls with hospital staff in the 144 hospitals/birthing centers. In accordance with its commitment to improving newborn hearing screening outcomes, the NYSDOH completes data reviews for all NBHS hospitals/birthing centers and distributes individual reports to them. The NBHSP completes these data reviews quarterly to measure baseline changes which influence strategies to improve hospital/birthing center performance. NYSDOH staff will continue to evaluate and compare newborn hearing screening data against the JCIH benchmarks.

The project will be further evaluated by the New York State Early Intervention System (NYEIS), which is currently under development. NYEIS will significantly enhance data collection and analysis for the BEI. This “real-time” database will capture, NBHS referral information, diagnostic information, types of evaluations conducted, insurance status, types of services children received, and demographic information about children served. NYEIS will meet all applicable state and federal regulations and meet Health Insurance Portability and Accountability Act and Health Care Financing Administration mandated requirements. NYEIS will employ proven hardware and software technology that ensures data security, meets defined performance standards, and is cost effective to maintain and operate. Additionally NYEIS will interface with external providers and users of information, e.g., the NYSDOH Medicaid Information Management System, and the New York State Education Department’s preschool special education and student information system. Thus far, the most likely candidate data system to house the NBHS data is the New York State Immunization Information System (NYSIIS). This module will include additional and expanded data fields to allow for the collection of individualized and more specific data for the NBHSP. It is also anticipated that NYEIS and NYSIIS will be able to exchange data through flat file or HL7 formats. This may facilitate automated referrals to EI and the collection of outcomes data for children birth to three with hearing loss. NYEIS will assist project evaluation by tracking information on hearing loss

screening, audiological assessment and early intervention services for those children referred to the Early Intervention Program.

PROGRAM NARRATIVE
ORGANIZATIONAL INFORMATION

In NYSDOH the NBHSP is located within the Bureau of Early Intervention (BEI) in the Division of Family Health which enables staff to provide technical assistance on newborn hearing screening to New York State Department of Health (NYSDOH) staff on an ongoing basis. Guidance has also been provided to BEI regional staff on the role of the EIP in facilitating follow-up for infants referred from hospital-based NBHSP in their communities.

New York State Department of Health. The NYSDOH is the lead agency for New York's implementation of the federal Office of Special Education, Part C, Individuals with Disabilities Education Act (IDEA) Early Intervention Program. See Attachment #6 for an organization chart for the Division of Family Health and the Center for Community Health. The NBHSP is integrated within the BEI and shares Bureau resources including technical assistance, training, public awareness material, data collection, quality assurance, analysis, and management.

Bureau of Early Intervention. All Units of the Bureau report to the Director and the Assistant Director in his absence. The Bureau Director is responsible for oversight of all BEI activities, as well as functioning as a liaison between the NYSDOH, federal and state agencies, the State Early Intervention Coordinating Council, service providers, local Early Intervention Programs (EIPs), parents, and other stakeholders. The Assistant Director is responsible for personnel management, assisting the Director in oversight of the BEI, and is the principal investigator on the current HRSA Newborn Hearing Screening (NBHS) grant and a Centers for Disease Control and Prevention (CDC) Grant on Early Hearing Detection and Intervention Tracking, Surveillance and Integration. A Project Manager (PM) has recently joined the NBHS staff. The PM manages the two NBHS grants. Each of the following BEI Units interfaces with the NBHSP.
The Quality Assurance Unit is responsible for service provider health and safety standards, provider confidentiality policy/procedure review, autism clinical record review, and provider and municipality monitoring.
The Technical Assistance and Training Unit is responsible for the development and delivery of EI trainings to various stakeholders throughout the state; provides technical assistance to service providers, municipalities, and parents; and coordinates the authoring and editing of BEI publications.
The Provider Approval and Due Process Unit is responsible for the review and approval of provider applications including audiologists, maintenance of a database of NYSDOH -approved early intervention service providers in the State, and establishment and oversight of procedural safeguards that enable EI stakeholders to resolve disputes.
The Program Development and Data Analysis Unit is responsible for overseeing implementation of the NBHS Program, the management of the Kids Integrated Data System (KIDS) and design and development of the New York Early Intervention System (NYEIS) which will replace KIDS, data collection and retrieval, production of the State Performance Plan and Annual Performance Report, creation of custom data reports for administration, and maintenance of current data storage systems.
The Administrative Services Unit is responsible for support to all other units including processing grant and contracted funding, drafting correspondence, copying, faxing, filing,

scheduling of meetings, personnel transactions, travel, purchasing, maintenance of electronic filing systems, and various other support functions as needed.

The NYSDOH has the organizational experience and capability to coordinate and support planning, implementation and evaluation of statewide newborn hearing screening activities, as evidenced by the following achievements. Since 2000, the NYSDOH has:

- Developed and implemented regulations for the Newborn Hearing Screening Program.
- Developed and disseminated public awareness materials in English and six other languages to support hospital newborn hearing screening programs.
- Developed and implemented a data input tool for use by all facilities administering newborn hearing screening programs to collect aggregate newborn hearing screening data on a quarterly basis.
- Established ongoing financing mechanisms for Newborn Hearing Screening via insurance and Medicaid.
- Provided ongoing technical assistance to 144 hospital-based Newborn Hearing Screening Programs and to 62 local Early Intervention Programs.
- Conducted conference calls with hospitals whose data do not meet the JCIH benchmarks, in order to facilitate communication, provide technical assistance, and monitor implementation.

The collection of aggregate newborn hearing screening data has resulted in linkages between hospitals required to administer newborn hearing screening programs and local EIPs. Given the geographic size, diverse population, and the complexity of NYS, forming connections and referral patterns at the local level is necessary for effective and timely newborn hearing screening follow-up and service delivery.

The NYS newborn hearing screening law (enacted in 1999) requires all hospitals/birthing centers to administer NBHSPs. Parents are given information about newborn hearing screening prior to the screening. Shortly after birth, the baby's hearing is screened and parents are given the result. If a baby does not pass the initial hearing screening, the parents will be given a prescription for their baby to have an outpatient screening and a list of qualified infant hearing screeners. If rescreen results are not obtained within 75 days after discharge, the hospital will refer the child to the Early Intervention Program in the child's county of residence as "at-risk." All hospitals/birthing centers must report aggregate NBHS data to the BEI on a quarterly basis for newborns discharged from their hospital.

The NYS NBHSP does not currently use an integrated child health data system. However, in July 2008, the NBHSP received CDC grant funding for the development of a universal newborn hearing screening data system. The NBHSP is in the process of the development of the data system and it is planned that this system will be integrated with the NYS statewide Immunization Registry. New York City has an existing Citywide Immunization Registry. This new data system will gather demographic information and strengthen the newborn hearing screening program's ability to develop and employ changes that are tailored to address the sensitive and diverse cultural issues that impact loss to documentation/follow-up. This statewide registry tracks childhood immunizations in NYS outside New York City. Currently NBHS staff are in

the process of drafting a Notice of Proposed Rulemaking to amend NBHS regulations so that individualized data can be collected from hospital/birthing centers instead of aggregate data.