New York State
Universal Newborn Hearing Screening and Intervention
Reducing Loss to Follow-Up after Failure to Pass Newborn Hearing Screening

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INTRODUCTION

The New York State Department of Health (NYSDOH)/Health Research Incorporated (HRI) proposes to conduct an initiative to reduce the number of infants lost to follow-up after failure to pass newborn hearing screening with grant funding from HRSA. The NYSDOH Newborn Hearing Screening Program will disseminate to all hospitals/birthing centers in New York State (NYS) the model of measures proven effective in reducing loss to follow-up developed by HRSA through the National Initiative for Children's Healthcare Quality (NICHQ) learning collaborative.

NYS has the third highest number of annual live births in the country (246,585 births in 2006). There are a total of 148 hospitals/birthing centers approved and regulated by the NYSDOH. In 1999, statute was enacted in NYS to require all hospitals/birthing centers to screen newborn infants for hearing loss as early in life as possible. Although NYS has the third highest number of annual births in the United States, it is the only one of the top three states to require the administration of newborn hearing screening. The screening rates for NYS are higher than all other large states due to this statutory requirement. The statute applies to all hospital/birthing centers in NYS, regardless of size or Neonatal Infant Care Unit (NICU) status. Regulations requiring all hospitals and birthing centers in New York to screen newborns for hearing loss were adopted in 2001. These regulations require hospitals to administer follow-up testing for all infants that either fail, or miss their initial screen either directly or through contractual agreement. Referrals to local Early Intervention Programs (EIP) are required both for infants with a suspected hearing loss and for infants with a failed initial screen 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.

Newborn hearing screening in NYS is primarily the responsibility of hospitals/birthing centers. Hospitals/birthing centers that care for newborns are required to administer, directly or by contract, newborn hearing screening programs. Under the Newborn Hearing Screening regulations, hospitals/birthing centers are responsible to conduct infant hearing screening, conduct follow-up infant hearing screening or provide referrals to obtain follow-up screening on an outpatient basis for those babies who fail or do not receive infant hearing screening prior to discharge from the facility. Hospitals and birthing centers are required to designate an individual to manage their newborn hearing screening programs, and to annually provide NYSDOH with updated contact information.

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

Newborn hearing screening in NYS is a collaborative effort between maternity hospitals and birthing centers and the statewide EIP, which is supported by grant funding from the U.S. Department of Education's Office of Special Education Programs, including local EIP administrators and counties. 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.

All hospitals and birthing centers with newborn hearing screening programs 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 the screening, the number of missed infants, and the number of infants referred for re-screening due to a failed initial screen. The current data tool is formatted in Microsoft Excel and submitted to the Newborn Hearing Screening Program (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 because of prolonged stays in a 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.

The NBHSP provides hospital/birthing center Newborn Hearing Screening Program Managers with an annual summary performance report of their newborn hearing screening program to assist Program Managers with 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 admission screen; infants who returned post-discharge for a re-screen; 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 and birthing centers to improve compliance with screening regulations. As a result, the NYSDOH has identified several difficulties that some hospitals/birthing centers face, including staff shortages, equipment failure, infants lost to follow-up and inadequate protocols for referral of infants with suspected hearing loss to the EIP serving their area.

NEEDS ASSESSMENT

NYS is one of the most racially diverse states in the nation. Preliminary vital records' data indicate that among the 246,585 live births in 2006, 162,417 (65.9%) were reported Caucasian; 51,955 (21.1%) were Black; and 31,883 (12.9%) were other (including Hispanic). In 2006, 0.7% of out of hospital births occurred in NYS.

The NYSDOH maintains a statewide NBHS 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 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 increased to 99.1% in 2006. 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 2006. 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 services. Follow-up rates for infants in NYS who failed to pass their birth

admission screen were 72.9% in 2002. This has remained at a similar rate of 71.6% in 2006. Of the 148 hospitals/birthing centers, approximately 44 outlier hospitals have lost to follow-up rates below the statewide average of 71.6%.

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. 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 negatively impact follow-up: shortages of staff used to administer screening tests, staff turnover and training of new staff, unavailability of screening on weekends, failure of equipment used for screening, lack of insurance coverage of additional follow-up screening, and ineffective protocols for referral of infants with suspected hearing loss to the local EIP. However, the following factors have been found to result in improved follow-up: conducting follow-up testing within the hospital's own facility rather than referring out, providing education to parents on the importance of follow-up for infants that fail, and maintaining direct relationships with pediatricians.

Due to the above, the NYSDOH is developing 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 and regulations.

Data are accessed from the statewide EIP to determine whether the implementation of statewide newborn hearing screening has had an impact on 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 12.65 months to 4.14 months of age for children with hearing loss.

Improvements are still needed to ensure that infants return for a timely re-screen after a failed initial screen. The lack of a newborn hearing screening state registry in NYS contributes to this problem. The current NBHSP data system does not collect data on an individual level. New York State Public Health Law only requires hospitals to report aggregate data to the NYSDOH including the totals of initial screenings, follow-up screenings, and children referred for audiological evaluations. Data on children identified with permanent hearing loss are only available for children referred to, evaluated by and enrolled in the EIP. Hospitals/birthing centers statewide continue to report aggregate data on newborn hearing screening quarterly including the following elements:

- Number of births.
- Number of discharges.
- Number of inpatient screenings conducted (pass, fail).
- Number of missed inpatient screenings.
- Number of outpatient screenings conducted (pass, fail).
- Number of referrals for outpatient screening.
- Number of results returned to the facility by other providers conducting outpatient screenings (pass, fail).
- Number of infants referred to the EIP for follow-up.

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 a result, the following are estimates of the number of infants who were lost to follow-up in 2006: 1) 1,622 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) between outpatient screening and audiologic 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, 3) 1,571 infants between diagnosis and entry into early intervention. These data also 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.

Newborn hearing screening technical assistance calls received from program managers from the 148 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 data transmittal to the NYSDOH, in order to enhance the provision of follow-up care. Challenges faced in providing follow-up services include: lapsed 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.

The 2003 National Survey of Children's Health shows that 2,394,272 (54.20%) children and youth ages 0-17 in NYS had a reported medical home, compared with 46.10% nationally.[1] The Joint Committee on Infant Hearing recommends a medical home for all infants with hearing loss. The medical home approach is one of providing health care services that are accessible, family-centered, continuous, comprehensive, and coordinated which allows pediatricians to recommend and work with an audiologist.

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 Early Intervention Program. Nonetheless, there are capacity issues in rural areas of the state. Many more audiologists are likely to be willing to see infants, but are just not approved as individual providers in the EIP

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.

METHODOLOGY

The NYSDOH will initiate a project that will focus on improving outcomes for infants with hearing loss and their families by improving rates of follow-up testing after a failure to pass newborn hearing screening. This project will identify and utilize quality improvement strategies in making changes and disseminate these successful strategies across NYS. The project will include the development of a recommended NBHS protocol that all NYS hospitals/birthing centers can implement to improve follow-up rates. An advisory work group will be formed

[1] Child and Adolescent Health Measurement Initiative (2005). *National Survey of Children's Health*, Data Resource Center on Child and Adolescent Health.

consisting of various constituencies involved with newborn hearing screening to provide input to the NYSDOH on the various activities and steps of the project. The project will incorporate aspects and strategies from the 2006 HRSA initiative, *Improving Follow-Up to Newborn Hearing Screening by Working through the Medical Home Learning Collaborative*, developed by the Maternal Child Health Bureau, as well as the National Initiative for Children's Healthcare Quality (NICHQ) model for improvement.[2] These modeled strategies have been shown to be effective in improving outcomes for infants with hearing loss and their families by improving follow-up in the newborn screening process. The NICHQ initiative strengthens the links between various components of follow-up to newborn hearing screening: definitive diagnosis, early intervention, entry into appropriate care and services, and connection to a Medical Home. During the three-year project period the following will occur: proposed strategies will be tailored to hospitals/birthing centers in NYS, a pilot phase of specific strategies will be initiated, a NYS NBHS recommended protocol will be developed, implementation of protocol strategies will occur, and evaluation methods will be implemented with all hospitals.

The work group members will review NICHQ and NYS-specific strategies and provide input on how these strategies can be piloted and implemented. A survey will be conducted to determine what hospitals/birthing centers already use each of the strategies below. The quality improvement strategies that will be incorporated from NICHQ in the NYS protocol are:

1. Obtain a second point of contact for the family at the first screening. A number of hospitals report difficulty in locating a family following discharge for follow-up purposes. Collecting a second contact for the family (e.g., a relative or a friend) prior to discharge and explaining the purpose of this contact will assist hospitals in tracking infants and obtaining follow-up.
2. Verify the identity of infants' pediatricians or primary care providers prior to discharge. Hospitals should transmit the results of newborn hearing screening information to the pediatrician/primary care provider as soon as possible. If the infant does not have a primary care provider, hospital staff will recommend one.
3. Use of a consistent prescription form that will be issued by birthing hospitals to obtain a missed initial screen or follow-up re-screening from other providers in the community authorized to provide infant hearing screening services. The form will also obtain parents consent to release screening results back to the birthing facility. The prescription will explain the importance of completing the hearing re-screen within one month following discharge from the birthing hospital.
4. Use of a fax-back form process to facilitate communication between primary care providers and specialty care providers. The fax-back forms will primarily be designed to alert primary care providers and audiologists of screening results and the need for prompt follow-up. The family will be given the form to take with them to an audiologist, who will then fax-back the form to the primary care physician/pediatrician. Hospitals will also fax results of infants' screenings to primary care providers, for those infants who may need follow-up after discharge.
5. Making follow-up appointments for families before they leave the hospital and explaining to them why it is important to keep the appointment. Schedule a second audiologist appointment at the same time as the first so that infants who are not be completely tested at the first appointment are already scheduled to return in a reasonable timeframe. Reminder

[2] The National Initiative for Children's Healthcare Quality (NICHQ), www.nichq.org

calls will be made before appointments to provide the reasons why appointments are important.

6. Obtain parental consent, prior to inpatient hearing screening, for referral to the EIP in the child's county of residence for follow-up purposes if the hospital cannot reach the family or for any other reason cannot schedule and complete a follow-up screening within the prescribed timeframe (75 days post discharge). In NYS, this referral will be tracked through the EIP database and local EIPs will be required to report a disposition of their efforts to secure follow-up testing.
7. Provide a script of the narrative information that hospital staff should provide to the parents of an infant who does not pass the initial screening test. The screening results will be conveyed immediately to families so that they understand the outcome and the importance of follow-up, when indicated. Communication with parents will be confidential and information will be shared in a caring and sensitive manner. Parents will be informed in a culturally sensitive and understandable manner that their infant did not pass screening and then parents will be informed about the importance of prompt follow-up.[3]

These strategies will be developed and piloted with the input of members of a newborn hearing screening work group as described in the Work Plan section of this Program Narrative. In addition, the NYSDOH will conduct outreach to physicians and provide training for qualified personnel in the EIP and for other Newborn Hearing Screening Program constituents.

To ensure that all children in NYS receive timely, coordinated, culturally competent care related to newborn hearing screening, diagnosis and early intervention services for hearing loss, the following additional strategies will be included in the NYS NBHS protocol.

1. In areas where resources or staff is lacking, cross-training of supervised nonprofessional staff will be recommended to perform testing or follow-up testing using automated pass-refer criteria.
2. Increase awareness of insurance coverage for newborn hearing screening and follow-up screening. Hospitals/birthing center staff will review insurance coverage by common carriers for initial newborn hearing screening provided at their facility. The birthing facility will discuss any charges a parent may incur as result of the screening. If referrals for follow-up screening are needed, parents will be made aware of the proper steps for obtaining the re-screen, including costs that may occur and sources of assistance in each community.
3. Improve how information is relayed to parents to assure that it is culturally sensitive and understandable. The NYSDOH will continue to produce NBHS brochures in various languages and translate existing publications into additional languages based on data describing the prevalence of foreign languages spoken in NYS households.
4. Provide physicians and primary health care providers with succinct information about the EIP and its services as they relate to newborn hearing screening, referral, eligibility, and services.

The NYSDOH will establish an advisory work group to assist and guide the development and implementation of this project. The purpose of the work group is to provide expert knowledge and first-hand expertise as the end-users of the NBHS system, and to participate in the development and dissemination of an effective screening and follow-up protocol for use in all NYS hospitals/birthing centers.

[3] Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics* 2007; 120: 898-921.

The work group will consist of the following members:

- Ten hospital/birthing center Newborn Hearing Screening Managers, including two each from the NYC Region, Finger Lakes Region, and Central Region; one each from the Hudson Valley Region, Northeastern Region, Western Region, and Nassau-Suffolk Region,
- One local EIP manager from both the upstate and downstate regions,
- One pediatrician/primary health care provider,
- One American Academy of Pediatrics Early Hearing Detection and Intervention District II Chapter Champion or representative, and
- One parent of a child with hearing loss from both the upstate and downstate regions.

Work group members will meet to learn about and create improved screening and follow-up processes. The work group will make recommendations to the NYSDOH on how to use and test the proposed strategies and protocol in their hospital/birthing centers before the NYSDOH implements these changes statewide. At the same time, the NYSDOH will collect information and data monthly on the use of the strategies and protocol to measure improvement. The work group meeting sessions will take place through: structured monthly conference calls; webinar (WebEx) conferencing; and in-person annual meetings. The work group will contribute in the following ways for improving follow-up rates.

- Review baseline aggregate data.
- Review and prioritize proposed strategies.
- Provide suggestions to the proposed strategies based on expertise and local experience.
- Assist in the development of prescriptions, faxes and other documents.
- Provide input on training initiatives.
- Assist with the planning and implementation phase of strategies.
- Review of data from pilots.
- Advise on strategies for dissemination and best practices to all hospitals/birthing centers statewide.
- Review and implementation of evaluation methodology.

During year one of the project, selected strategies will be piloted in 10 identified hospitals. Each strategy will be evaluated using a methodology developed by the NYSDOH. After 90 days, the work group will review data from the pilot phase and recommend any needed revisions to the strategies. Revised or refined strategies will be piloted for an additional 90 days. Results of the evaluation of the second phase of the pilot will be reviewed by the work group and any additional changes will be discussed. If strategies are successful in the two phases of the pilot, they will be considered effective and will be included in the protocol for implementation throughout NYS.

In year two of the project, the primary objective will be to implement the NBHS protocol among an additional 50 hospitals/birthing centers. The initial 10 hospitals/birthing centers will implement the finalized NBHS protocol in affiliated hospitals within their health system. The NBHSP will provide the finalized NBHS protocol to additional hospitals statewide through e-mail, direct mail, conference calls, and webinar (WebEx) conferencing.

In year three, the primary objective will be to implement the NBHS protocol among the remaining hospitals/birthing centers in NYS. Quarterly and annual data/information will be collected and evaluated.

WORK PLAN

The proposed screening strategies and protocol will improve statewide newborn hearing screening by increasing the number of infants who receive timely and appropriate follow-up services when they do not pass their initial hearing screening.

The six components of the project are Pre-Work Group Session Activities; Work Group Sessions; Pilot Action Periods; Development of Protocol; Implementation and Evaluation Phase; and Technical Assistance and Training Activities.

Work Plan Years 1-3 **Project Activities**	**Responsible Staff**	**Time Line**
Pre-Work Group Session Activities		
• Identify work groups members consisting of 10 Newborn Hearing Screening Managers, two local EIP Managers, a pediatrician/primary health care provider, an American Academy of Pediatrics Early Hearing Detection and Intervention District II Chapter Champion or representative, two parent representatives who have a child with hearing loss, and NYSDOH Bureau of Early Intervention staff.	NYSDOH Newborn Hearing Screening (NBHS) staff	Within the first two months of the project
• Develop a schedule of meetings, including one face-to-face meeting, and conference calls for each grant period.	NYSDOH Newborn Hearing Screening (NBHS) staff	Within the first two months of the project
• Develop communication procedures for work group members	NYSDOH Newborn Hearing Screening (NBHS) staff	Within the first two months of the project

Work Group Sessions		
• Five Work Group Session Conference Calls will be convened the first year. Topic – use of NICHQ Strategies in NYS hospitals/birthing centers. Proposed strategies specific to NYS will be revised and adapted. A needs assessment will be conducted among hospitals/birthing centers.	NYSDOH NBHS staff and work group members	(1) Summer 2008 (2) Fall 2008 (2) Winter 2009
• One Work Group Session Meeting (face-to-face) will be convened at the end of the first year. Topics - NICHQ Strategies and NYS Specific Strategies	NYSDOH NBHS staff and work group members	Spring 2009
• Three Work Group Session Conference Calls will be convened during the project's second year.	NYSDOH NBHS staff and work group members	Second year of project (2009-2010)
• Three Work Group Session Conference Calls will be convened in the third year of the project.	NYSDOH NBHS staff and work group members	Third year of the project (2010-2011)
Pilot Action Periods		
• Five NICHQ Strategies/NYS Specific Strategies will be piloted in the first year of the project. Specific strategies will be piloted for three months, data collected and evaluated. Strategies revised, if any. Strategies piloted and evaluated again for three months.	NYSDOH NBHS staff and the ten identified pilot hospitals/birthing centers from work group	One pilot session in the Fall of 2008. Two pilot sessions each in Winter 2009 and Spring 2009
Development of Protocol		
• Development of NBHS protocol. Successful proven strategies will be included as well as the developed forms and prescriptions, and useful information on diversity of populations.	Work group members and NYSDOH NBHS staff	Fall 2009

Statewide Implementation and Evaluation Phase		
• Implement phase #1 – Conduct a WebEx session with 50 hospitals/birthing centers regarding implementation of the protocol and usage of successful strategies.	NYSDOH NBHS staff and 50 hospitals/birthing centers staff	Fall 2009/Winter 2010
• Collect, review and evaluate three months of data for the 50 identified hospitals/birthing centers.	NYSDOH NBHS staff and work group members	Fall 2009/Winter 2010 Winter/Spring 2010
• Implement phase #2 – Conduct a WebEx session with the remaining hospitals and birthing centers on implementation of the protocol and use of successful strategies.	NYSDOH NBHS staff and all remaining hospitals/birthing centers staff	Summer 2010-Spring 2011
• Collect, review and evaluate quarterly and annual data for all hospitals/birthing centers.	Work group members and NYSDOH NBHS staff	
Technical Assistance/Training Activities		
• Provide ongoing technical assistance to hospitals/birthing centers, parents, medical home staff and local Early Intervention Programs.	NYSDOH NBHS staff	Spring 2008-Spring 2011
• Conduct training for hospitals/birthing centers, parents, medical home staff and local Early Intervention Programs.	NYSDOH NBHS staff and NYS Early Intervention Training Contractors	Spring 2008-Spring 2011
• A quality assurance tool will be implemented among hospitals during on-site technical assistance visits.	NYSDOH NBHSP staff	Spring 2008-Spring 2011

RESOLUTION OF CHALLENGES

The NYSDOH faces several challenges in implementing its proposed plan and objective to increase to 100% the number of hospitals/birthing centers in NYS adopting these strategies within this three year project period. One major challenge is the limitation preventing the NBHSP from collecting data on individual infants. The data tool used to collect the aggregate data from the hospitals/birthing centers is limited in what can be recorded by the hospital/birthing centers. Many of the hospital/birthing centers with a large NICU population find it difficult to report required data for these infants. Data are collected quarterly based on discharges from the hospital. NICU infants may not be screened and discharged until well after the quarter they are born in thus making reporting of these infants difficult and in some cases, overlooked.

NYS is no different from many other large states with a diverse population. The many different languages and cultural diversity of the residents present a communication problem. In New York City alone, there are 10 major languages spoken. It has been noted through technical assistance calls with hospital/birthing centers that many of these families do not bring their infants in for follow-up because they do not comprehend what needs to be done.

It has also been noted that low socio-economic status families tend to return for follow-up due to services being paid through Medicaid. Families of higher socio-economic status may be more likely to seek follow-up testing through their own physician because they are more likely to have insurance coverage or be able to pay for the services. In many instances, the physicians do not report back to the hospitals and follow-up for these infants is not recorded.

NYS also has large rural regions, where there is a shortage of hospitals/birthing centers, lack of approved audiologists and no accessible public transportation. This plays an important role in families in this region not returning with their infants for follow-up. There is also more likely to be a lack of coordinated communication between the hospitals/birthing centers in such rural areas, and the primary care physician.

Another challenge is the planned consolidation of hospitals/birthing centers in NYS that have been recommended as a cost-saving measure. A Commission on Health Care Facilities (aka the Berger Commission), created by statute in 2006, was directed to make statewide recommendations aimed at eliminating excess bed capacity through "rightsizing" of hospitals. It also involves the consolidation and sharing of services between specific facilities.

The following activities will help strengthen the NYSDOH's efforts to address these challenges. A core group of BEI staff will conduct regularly scheduled program meetings. BEI staff meets weekly to discuss ongoing issues in the NBHSP. These staff consist of the Principal Investigator, NBHSP staff, and others as their expertise is needed. Topics covered include revisions to the data tool, the provision of technical assistance to hospitals, conference calls with hospitals to discuss data outliers, analysis of aggregate data, and other topics, as needed.

NBHSP staff also will consult with the NYSDOH Office of Health Systems Management (OHSM) to address any concerns with hospitals/birthing centers. OHSM formulates and administers health policies that promote a safe, cost-effective, and high quality health care delivery system throughout the health care continuum and provides oversight of hospitals, diagnostic and treatment centers and other acute care facilities.

NYSDOH will convene meetings of the NBHS advisory work group. Work group members will meet to learn about and create improved screening and follow-up processes. The work group will make recommendations to the NYSDOH on how to use and test the proposed strategies and protocols.

NYSDOH staff will develop a NBHS monitoring tool. Staff from the BEI Quality Assurance Unit has considerable experience with the development and implementation of quality assurance protocols. They will advise on best practices and possible pitfalls regarding the design, testing, and implementation of quality assurance tools and protocols.

Staff will work to promote the proposed strategies, protocol, and availability of technical assistance to hospitals/birthing centers through their member organization, Greater New York Hospital Association (GNYHA) and Healthcare Association of New York State (HANYS). HANYS, the only statewide hospital and continuing care association in New York State, represents more than 550 non-profit and public hospitals, nursing homes, home care agencies, and other health care organizations. GNYHA is a one-of-a-kind trade association comprising nearly 300 hospitals and continuing care facilities, both voluntary and public, in the metropolitan NY area and throughout the State, as well as New Jersey, Connecticut, and Rhode Island **(See Letter of Support Attachment #7)**.

Finally, staff will investigate innovative strategies to recruit and retain additional audiologists for the local EIP service through the Local Early Intervention Coordinating Councils (LEICC) and universities with accredited audiology programs. LEICC's are responsible for identifying and making recommendations to counties regarding insufficient numbers of EI providers to administer services in the area. Both LEICC's and universities with accredited audiology programs have the ability to increase provider's awareness of the EIP, and assist in increasing the amount of audiologists that become approved EI providers.

The NBHS work group will develop and pilot screening strategies and protocol in 10 hospitals/birthing centers. Challenges may be encountered in establishing and facilitating the work group. Additionally, proposed strategies may impact the hospital's/birthing center's NBHS processes and administration of the program. To help resolve these barriers the NYSDOH will select hospitals/birthing centers for the work group that have been active within the NBHSP. Information will be reported by the work group on the effectiveness of the piloted strategies and protocol for evaluation. The strategies can be monitored monthly using the NBHS data tool. The data captured in the pilot will be evaluated to determine effectiveness and possible barriers to each strategy and the use of the protocol. Work group members will provide input into revision and refinement of each strategy and the protocol.

The project is further challenged when an infant suspected of having a hearing loss is referred by the hospital to the local EIP for appropriate evaluation and services and either receives no follow-up, or there is no report back to the hospital of the disposition of the referral. Additionally, there is no statewide system available that tracks newborn hearing screening and follow-up. However, the NYSDOH is evaluating the current NYS NBHS law and regulatory limitations for collecting aggregate data only. NYSDOH staff will collaborate with the NYSDOH Immunization Program to explore the inclusion of newborn hearing screening reporting through a new Web-based Immunization Registry. Beginning January 1, 2008, health care providers are required to report all immunizations given to persons less than 19 years of age, as well as their immunization history.

The NYSDOH conducts technical assistance calls with hospitals/birthing centers to learn about their newborn hearing screening process. This is also an opportunity for hospitals/birthing centers to ask questions of the NYSDOH Newborn Hearing Screening Program staff. As follow-up to the technical assistance calls, the NBHSP is developing a quality assurance tool for on-site review and assessment of hospitals/birthing centers newborn hearing screening programs. Due

to the various levels of care, physical location, and the population in the areas they serve, each hospital/birthing center has a unique protocol in place to meet the regulatory requirements of Newborn Hearing Screening Program. The NYSDOH's development of a standardized screening protocol that will also provide individual hospital/birthing center tailoring of additional information will enable consistent screening and follow-up activities statewide.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Proposed strategies, protocol, and work plan activities will be measured through process and impact evaluation that include: change in data reported by hospitals to the NBHS Program and the Kids Integrated Data System; on-site visits to the 10 hospitals/birthing centers participating in the advisory work group to review usage of the strategies; hospital/birthing center usage of a self-assessment progress tool; change in the type and number of requests to the NBHSP for technical assistance; tracking the number of hospitals/birthing centers adopting proposed practices; observing the change in performance of hospitals/birthing centers through pre/post measures; and changes in established baselines.

Proposed strategies, protocol, and work plan activities will be measured through a variety of process and impact evaluations. The current quarterly newborn hearing screening data tool will be utilized monthly by hospitals/birthing centers as they initiate work plan activities. The data tool tracks follow-up screenings and, by increasing the frequency of the data reviews, NBHSP staff will be able to track the success of the implemented changes in a much more timely and propitious manner and expand useful feedback on reported data. 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 KIDS will be used to compare rates for referral to the EIP for evaluation and services both prior and following the implementation of the NBHS follow-up strategies. Data will be generated based on various time periods and also allow break down by regions.

On-site visits to the hospitals/birthing centers will take place during the piloting period. During these visits, medical records will be reviewed and screening procedures will be observed by NBHSP staff. The continued expansion of interaction between hospitals/birthing centers and NBHSP/BEI will provide additional feedback to hospitals/birthing centers on reported data. Noted trends, anomalies, and outliers of reported data will be discussed with selected hospitals/birthing centers during and after site visits. In addition, technical assistance can be offered to the facilities regarding the new strategies. A self-assessment tool will be utilized to track progress and success of the strategies. This assessment tool will be completed by each of the hospitals/birthing centers staff that administers NBHS. The results of the assessment will be used to assess the effectiveness of the work plan strategies and assist in resolving difficulties. The DOH NBHS Program staff also will continue to track and measure the technical assistance calls that are received. The tracking will include date of call, location of requestor, issue, and resolution.

Prior to the introduction of the NBHS protocol a pre-assessment will be completed by each hospital/birthing center. The pre-assessment will consist of questions concerning their 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 American Academy of Pediatrics Early Hearing Detection and Intervention District Chapter Champions across NYS in the roll out of the protocol. The Chapter Champions will encourage and support their assigned regional hospitals in implementing the NBHS protocol.

The NYSDOH conducts statistical analysis of data collected through Kids Integrated Data System and prepares the 148 NBHS individual hospital summary data reports. The NYSDOH will evaluate the project strategies identified in the Methodology section of this proposal. The key indicators used in the evaluation include: 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 screening). 3) percent returned post-discharge re-screen (i.e., how well are children being followed up, when needed). Trend analysis over time and comparisons between hospitals/birthing centers will identify trends, anomalies, and outliers. Follow-up on these will help identify data errors, events that have a one time impact on the system, and longer term effects of new policies/approaches. Ideally, this follow-up can identify best practices and solutions to specific problems, which could be shared among the hospitals/birthing centers.

The proposed NICHQ project strategies will be evaluated by tracking the rates of effectiveness of:

1) Obtaining the second point of contact for the family at first screening. 2) Verification of the infant's pediatrician/primary care provider prior to discharge. 3) Usage of the consistent prescription form. 4) Usage of the fax-back screening results form. 5) Scheduling of follow-up appointments before families leave the hospital. 6) Obtaining parental consent for early intervention notification prior to inpatient hearing screening. 7) Usage of the narrative script for parents of an infant not passing the initial screening.

The proposed NYS-specific strategies will be evaluated by tracking the rates of effectiveness of:

1) Conducting cross-training supervised nonprofessional staff to provide testing. 2) Parents who are informed of insurance coverage and charges. 3) Usage of culturally sensitive and language-specific print education material. 4) Provision of NBHS-specific referral information to physicians and primary health care providers.

The NYSDOH will establish, in conjunction with the work group, baseline measures for each strategy during the project development phase. Changes in the baseline will be evaluated for effectiveness and used to refine strategies and help guide project-related best practice.

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

The methodology used for the development of the CPGs was one established by the Agency for Healthcare Research and Quality (AHRQ). This was done to ensure that the guidelines would be credible to families, service providers, and public officials. The AHRQ "methodology was selected because it is an effective, scientific, and well-tested approach to guideline development." The scientific studies reviewed by the panel were those that met preset criteria for adequate evidence. These were reviewed thoroughly, and the results were abstracted onto evidence tables. The panel then made conclusions about the strengths and limitations of each study, as well as the degree of applicability of the evidence. The basis for developing the guideline recommendations was formed by combining information from peer reviewed published articles, along with information on potential harms, and estimated costs for methods. For the

topics where the evidence-base approach was regarded to be appropriate, standard decision making rules were applied. Where scientific evidence was available, it was given the most weight. Each of the guideline recommendations was assigned a *Strength of Evidence* rating, indicating whether the recommendation was evidence-based. Where the scientific evidence was not found, or when the topic was not a focus of the evidence review, the recommendations were developed based on the opinion of the expert panel. In all instances, the recommendations in the guideline were the consensus of the panel.

The expert panel of the hearing loss guidelines consisted of 14 panel members, including two audiologists, one neonatologist, one otologist/neurotologist, one developmental psychologist, two speech-language pathologists, three parent representatives, three special education teachers and one social worker. 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 wider NYSDOH can access the CPGs on the Web site and also through 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. The CPGs have also been disseminated through the 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, announcing the availability of the CPGs including the Web site address for locating the CPGs on the NYSDOH-BEI Web page.
e. Copies were also sent to all panel members.

The BEI is sending letters to individual physicians, group practices, and other individuals announcing the availability of the CPG on Hearing Loss. The NYSDOH frequently receives requests to reprint sections and/or chapters of the guidelines from local organizations, state agencies, early childhood development groups, associations, and colleges/universities from many states and even other countries.

There are additional guideline books that have been issued in three versions; each one has a different level of detail describing the literature review methods and the evidence that supports the recommendations. Compact discs consisting of all versions for the four most recent titles are available. CPGs have been developed and disseminated for Autism/Pervasive Development Disorders (1999), Communication Disorders (1999), Down syndrome (2006), Motor Disorders (2006) and Hearing Loss (2007).

The New York State Early Intervention System (NYEIS), which is currently under development, will further evaluate the project by tracking information on hearing loss screening, audiologic assessment, and early intervention services for those children referred to the EIP.

The NYSDOH provides technical assistance to the 148 hospitals/birthing centers statewide through individual telephone technical assistance, and through conference calls with hospital staff. In its commitment to improving newborn hearing screening outcomes, the NYSDOH completes data reviews for all NBHS hospitals/birthing centers and disseminates the reports to them. The Newborn Hearing Screening Program completes these data reviews quarterly and the information is used to measure baseline change and to improve hospital/birthing center performance. NYSDOH staff will also continue to compare and evaluate newborn hearing screening data against the Joint Committee on Infant Hearing benchmarks.

Staffing Plan and Personnel Requirements

The NBHSP team will have up to nine staff collaborating on this project. The team members have diverse skills and Ph.D.-/Masters-level degrees. The team brings documented experience and demonstrated competencies to the project. The staffing plan highlights team member skills and expertise needed to match the proposed project tasks. These staff are particularly qualified to conduct needs assessment; implement, coordinate, and manage the project; provide training and technical assistance; collect and analyze data; and design evaluation systems and disseminate results. This grant application requests funding for two key staff:

- Edith Benjamin is a Health Program Administrator with the NYSDOH Newborn Hearing Screening Program. The Health Program Administrator's role in the proposed project will be to serve as liaison with hospital/birth center Newborn Hearing Screening Managers to facilitate implementation of proposed changes to NBHS; assist in the review of hospitals/birthing centers for compliance with policy, standards, regulations, and new initiatives; and conduct on-site visits to hospitals/birthing centers.
- Justin Hausmann is a Clerk II in the NYSDOH Newborn Hearing Screening Program. The Clerk II's role in the proposed project will be to: provide technical assistance through live and on-line electronic communication with the ability to share software applications which provides hospitals with a better understanding of the data tool and reporting; coordinate the new fax-back procedures and obtaining second contact information; connecting to a medical home; and, drafting the new re-screen prescription form and the verbal script for use in follow-up appointments.

The job descriptions for the Health Program Administrator and Clerk II are at **Attachment #3** and provides in greater detail the roles and responsibilities of these two NBHSP staff. As indicated in the budget justification, the Clerk II will contribute 100% time to this initiative for the first two years and 85% in the third year.

In-kind Departmental Support: Seven NYSDOH staff will provide in-kind support to the project. Brief biographical sketches and qualifications for Ms. Knudson Chouffi and Ms. Mack are at **Attachment #4**.

- Brenda Knudson Chouffi, M.S., is the Assistant Director of the Bureau of Early Intervention (BEI) and will contribute 15% in-kind, as the Principal Investigator. Ms. Knudson Chouffi's principal duties for this project include: oversight of all grant deliverables; provide programmatic guidance and direction; and participate in evaluation and reporting.
- Cynthia Mack is an Early Intervention Specialist and is Coordinator for the NBHS Program. She will contribute 60% in-kind. Ms. Mack's principal duties for this project include: supervision of the Health Program Administrator and Clerk II; participate in all phases of strategy implementation and protocol development, and work plan delivery; review and assign project work activities; and manage the grant budget and timeline.

Additional key NYSDOH staff providing in-kind contribution to the project includes:

- Bradley Hutton, M.P.H., is the Director of the Bureau of Early Intervention. Mr. Hutton has responsibility for overall management and direction of the BEI and will contribute 5% to this project.
- Jeff Simon, M.S., is the Manager of the Training and Technical Assistance Unit within the BEI. He will contribute 5% time to the project.
- Coral Horner, R.N., is a Public Health Program Nurse, and will provide assistance developing a monitoring tool used to monitor the hospitals/birthing centers newborn hearing screening program. She will contribute 5% in-kind.

- Mycroft Sowizral, Ph.D., is a Research Scientist III with the BEI and will contribute 10% in-kind. Dr. Sowizral will develop a project evaluation plan, analyze reported aggregate data, generate data reports and evaluate the effectiveness of the strategies.
- Donna Noyes, Ph.D., is the Associate Director for Clinical Policy for the BEI. Dr. Noyes will provide 10% time in-kind contribution and will coordinate project evaluation, interpret NBHS regulations, and provide policy analysis, particularly for the statewide protocol.

Hearing Loss Training. Training on the use of the Hearing Loss Clinical Practice Guidelines has been delivered to approximately 800 individuals from December 2006 through September 2007 through the NYSDOH training activities in early intervention. This face-to-face training is offered free of charge to parents, service coordinators, evaluators, primary referral sources, college faculty and students, early intervention service providers, and municipal staff participating in the NYS Early Intervention Program.

Cultural Diversity Training. The NYSDOH sponsors two contracted trainings on Cultural Diversity: Approaches and Differences; and, Linguistic Differences that meet the diverse needs of service providers, evaluators, healthcare professionals, parents in the early intervention system; and, other stakeholders. The learning outcomes for these two, 3-hour courses include: learning about cultural customs/practices and how to effectively and sensitively interact with diverse families when communicating and coordinating early intervention and other services.

Publications. Staff of the Bureau of Early Intervention published the *Clinical Practice Guideline, Hearing Loss: Assessment and Intervention for Young Children (Age 0 to 3 Years),* summer, 2007. This guideline provides evidence-based information on best practices from assessment and intervention for young children with hearing loss and their families. The Guideline consist of three books: *The Technical Report* provides the full text of the recommendations and a complete description of the methodology and the evidence used to develop the recommendations, The Evidence Tables are presented in a stand-alone document as a companion to the Technical Report, *The Report of the Recommendations* provides the full text of the recommendations plus an abbreviated description of the methodology and evidence used to develop the recommendations, *The Quick Reference Guide* provides summary information of the major recommendations. A Compact Disc containing all of the books and evidence tables is also available. The books and CD are disseminated to all BEI approved audiologists statewide, parents of children with hearing loss, service providers, evaluators, and other stakeholders. With previous HRSA funding, the BEI developed and disseminates to the 148 hospitals/birthing centers and other stakeholders, four versions of the NBHS brochures and posters in seven languages – Bengali, English, French Creole, Mandarin Chinese, Russian, Spanish, and Urdu. The brochures received the Bronze Award from the National Public Health Coalition's 2003 "Awards for Excellence in Public Health Communication."

Family Support Activities. The NYSDOH also supports a Family Initiative Coordination Services Project, which collaborates with parents and promotes parent involvement at all levels of the Early Intervention Program. One of the initiatives under this project is the delivery of Early Intervention Partners training for parents in the early intervention system. This leadership-training project helps parents of varied diverse backgrounds to learn more about opportunities for parent involvement within New York State's Early Intervention Program, including newborn hearing screening. The training sessions also provide information, resources and skill-building activities designed to increase advocacy and leadership skills. Parents of children with disabilities, including hearing loss, participate in Partners training over three separate weekends at an upstate and a New York City location.

National Presentation. The NBHS Program principal investigator and the program coordinator presented an overview of the *New York State Early Intervention Program Clinical Practice Guidelines* during a Topical Session at the Early Hearing Detection and Intervention Conference, Salt Lake City, Utah, March 26-27, 2007. The presentation focused on 1) the rationale for the use of evidence-based clinical practice guidelines in the delivery of early intervention services, 2) accessing the three versions of the Clinical Practice Guideline on Hearing Loss, and 3) the purpose of using the Hearing Loss guidelines to help determine appropriate assessment and intervention strategies for young children with hearing loss.

World Wide Web. The Bureau of Early Intervention maintains a Web page through the Department's Web site, www.nyhealth.gov/community/infants_children/early_intervention/. The Web page contains a description of the Newborn Hearing Screening Program, including NBHS regulations, field guidance for service providers and families (EIP Memorandum 2003-3 which further explain regulations), NBHS brochures (including Spanish) in portable document formatting, and a listing of a variety of family support organizations. The BEI Web page received 32,813 visits between January and September 2007.

ORGANIZATIONAL INFORMATION

Data from the 2007 JCIH Position Statement indicate that linking the Newborn Hearing Screening Program with effective provision of early intervention services may decrease the impact of hearing loss on language and other areas of development.[4]

Given the effective linkages above, the Newborn Hearing Screening Program is located within the Bureau of Early Intervention in the Division of Family Health which enables staff to provide technical assistance on newborn hearing screening to 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 Newborn Hearing Screening Programs 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 Newborn Hearing Screening Program is integrated within the Bureau of Early Intervention and shares Bureau resources including technical assistance, training, public awareness material, data collection, 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 liaison between the NYSDOH, federal and state agencies, the State Early Intervention Coordinating Council, service providers, local Early Intervention Programs, parents, and other stakeholders. The Assistant Director is responsible for personnel issues, assists the Director in oversight of the BEI, and is principal investigator on the current NBHS grant. Each of the following BEI Units interfaces with the NBHSP.

The Quality Assurance Unit is responsible for provider health and safety standards, provider confidentiality policy/procedure review, autism clinical record review, and provider and municipality monitoring.

[4] Yoshinaga-Itano, C., Sedey, A. L., Coulter, D.K., & Mehl, A.L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics, 5*, 1161-1171.

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; coordinates the authoring and editing of BEI publications; and, oversees implementation of the NBHS Program.
The Provider Approval and Due Process Unit is responsible for the review and approval of provider applications including audiologists, maintenance of a database of Department-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 the management of Kids Integrated Data System and design and development of the New York Early Intervention System 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 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 New York State Department of Health 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 148 hospital-based Newborn Hearing Screening Programs and to 62 local Early Intervention Programs.
- Conducted conference calls with hospitals whose data are outside 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 Early Intervention Programs. Given the geographic size, diverse population, and the complexity of New York State, forming connections and referral patterns at the local level is necessary for effective and timely newborn hearing screening follow-up and service delivery.
The New York State newborn hearing screening law requires all maternity hospitals and birthing centers to administer newborn hearing screening programs. 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, he/she may be re-screened prior to discharge. If the baby cannot be re-screened before discharge, or does not pass re-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 re-screen 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 birthing centers must report aggregate NBHS data to the Bureau of Early Intervention on a quarterly basis for newborns discharged from their hospital.

The New York State NBHS Program does not currently use an integrated child health data system. However, in January 2008 the Department will implement the NYS Immunization Registry statewide. New York City has an existing citywide immunization registry. This statewide registry will track childhood immunizations in NYS outside New York City, and may have possible application for NBHS. Also, the BEI is scheduled to release in 2008 the New York Early Intervention System (NYEIS), which will replace the current Kids Integrated Data System (KIDS). 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. The 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. NYEIS provides a basis to deploy additional functional modules as needed, improves local agency billing and claiming, provides a database that is more dependable, resulting in more accurate and flexible reporting and record exporting. 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.

Dissemination of Results and Replication. The NYSDOH will, during and at the end of the project, disseminate results of piloted strategies and protocol for NBHS screening and follow-up. The usefulness of results has application for duplication in various hospitals/birthing centers, locally, statewide, regionally and/or nationally. These results will be disseminated through the following mechanisms: publication in relevant NYSDOH reports; publication in professional journals; presentations at local, state, and national meetings/conferences (including the NYS Early Intervention Coordinating Council); posting at the NYSDOH Web site; promotion through e-mail and specialized list-serves; regularly scheduled training sessions for early intervention professionals and parents; and access to newsletters of associations and organizations.

The NYSDOH will continue to seek ways to sustain the NBHSP beyond the availability of federal funding. Options that will be considered include, but are not limited to: dedicated support through annual requests for state appropriations; continuance of in-kind staff contributions; applying for support from not-for-profit foundations or associations; Maternal and Child Health Block Grant; and, partnerships through membership organizations representing hospitals.