

List of Acronyms

AAP: American Academy of Pediatrics
ABR: Auditory Brainstem Response
CDC: Centers for Disease Control and Prevention
CMU: Case Management Unit
DDHH: Division of the Deaf and Hard of Hearing
DOH: Department of Health
EHDI: Early Hearing Detection and Intervention
EHS: Early Head Start
EI: Early Intervention
EIM: Early Identification and Monitoring Program
FCC: Family Centered Care
FHS: Family Health Services
HEC: Hearing Evaluation Council
HIV: Human Immunodeficiency Virus
HRSA: Health Resources and Services Administration
IFSP: Individualized Family Service Plan
IHSIS: Improving Hearing Screening and Intervention Systems
LTD: Loss to Documentation
LTF/D: Loss to Follow-up/Loss to Documentation
LTF: Loss to Follow-up
MCHBG: Maternal Child Health Block Grant
MCHV: Maternal Child Home Visiting
NICHQ: National Institute on Children's Healthcare Quality
NJAC: New Jersey Administrative Code
NJEIS: New Jersey Early Intervention System
NJIIS: New Jersey Immunization Information System
NJSA: New Jersey Statutes Annotated
NS&GS: Newborn Screening and Genetic Services
PCP: Primary Care Provider
PDSA: Plan-Do-Study-Act
PHCN: Public Health Consultant - Nursing
PHHCD: Pediatric Hearing Health Care Directory
PPD: Postpartum depression
QI: Quality Improvement
REIC: Regional Early Intervention Collaborative
SCHEIS: Special Child Health and Early Intervention Services
SCHS: Special Child Health Services
VIP: Vital Information Platform
WIC: Women, Infants and Children

Program Narrative

Introduction:

Significant hearing loss is one of the most common health conditions present at birth, with national reports of hearing loss identified through newborn hearing screening of 1.5 per 1,000 screened infants¹. In New Jersey, with approximately 100,000 annual occurrent live births, an estimated 150 babies are born each year with hearing loss. Undetected hearing loss impedes speech, language, and cognitive development. Delays can be minimized or avoided through early detection and intervention.

The New Jersey Department of Health (DOH) has a strong infrastructure to support newborn hearing screening. Public Law 2001, chapter 373 (NJSA 26:2-103.1 et seq.) requires universal newborn hearing screening and administrative rules (NJAC 8-19:1) provide specific and enforceable criteria for hospitals, physicians, and audiologists to ensure screening and follow-up. Screening in New Jersey is very successful, with a screening rate in 2012 of 99.4%. Achieving the national goals of ensuring completion of diagnostic audiologic testing by three months of age and enrollment in Early Intervention (EI) by six months are improving, but continue to be an area of needed interventions. Impediments that contribute to Loss to Follow-up (LTF) include families not recognizing the importance of follow-up evaluation, lack of local pediatric audiology facilities, delayed referral for diagnostic audiologic testing for children presenting with chronic middle ear infections, failure of physicians to refer families for follow-up testing, and financial or insurance barriers. Other challenges include the failure of providers to provide documentation of follow-up exams to the New Jersey Early Hearing Detection and Intervention (EHDI) program, families receiving out-of-state follow-up, and families residing or moving out of state after the birth, which contribute to Loss to Documentation (LTD).

The purpose of the proposed Health Resources and Services Administration (HRSA) grant is to further focus efforts on reducing the number of infants who are LTF or LTD after a failed hearing screening. The New Jersey EHDI Program will use funding to maintain the salary and overhead for one staff member, a Public Health Consultant - Nursing (PHCN), who is supported by current HRSA funding. Specifically, she will continue to develop, implement and measure small tests of change using Plan-Do-Study-Act (PDSA) cycles. She will continue the work that was begun during New Jersey's participation in the National Institute on Children's Healthcare Quality (NICHQ) Learning Collaborative, through ongoing collaboration with the New Jersey EHDI Quality Improvement Stakeholder group that has continued to meet since the conclusion of the NICHQ collaborative. Funding will also be provided through subgrants to a case management unit and the New Jersey Early Intervention System (NJEIS).

¹ <http://www.cdc.gov/ncbddd/hearingloss/ehdi-data2012.html>

Need Assessment:

Demographics: New Jersey is geographically small and according to United States Census data², is the most densely populated State with 1,195 persons per square mile. With 8.8 million people, it is the eleventh most populous State, with three percent of the national population. Census data from 2010 reported 59.5% of the population was White non-Hispanic, 17.7% were Hispanic, 12.8% were Black non-Hispanic, and 8.2% were Asian. Of mothers who delivered at New Jersey hospitals during 2013, 37.6% were born outside of the United States and its territories, with the largest contribution being mothers that were born in India (4.8% of all births), Mexico (4.5%), the Dominican Republic (3.2%) and Ecuador (1.6%). Census data on language spoken in New Jersey households reveal that 12% of the population speaks English “less than very well” with the most common primary languages in these homes being Spanish (7.1% of the population), Chinese (0.6%), Korean (0.5%), Portuguese (0.4%), and Gujarati (0.4%). Racial, ethnic, and linguistic diversity contribute to the cultural richness of New Jersey, but can be present barriers to follow-up. In 2012, according to the Kaiser Family Foundation³, 8% of New Jersey children were uninsured, just below the national average of 9%.

Birth Facilities and Audiology Facilities: New Jersey currently has about 100,000 births each year. There are currently 52 hospitals providing maternity services, with two hospitals having closed their obstetric services during 2014. Home births are very uncommon, representing about 200 (0.2%) of New Jersey births annually. Only half (26) of the hospitals with maternity services have an audiology department, and only 15 of those offer comprehensive diagnostic audiologic services appropriate for young infants. Of the 26 hospitals without audiology services, 17 utilize the nursery hearing screeners to conduct one outpatient rescreening prior to referral to an audiology facility. In four of the hospitals that have audiology services, the nursery screening staff may still complete a rescreening prior to referral to the audiology department. There are an additional 11 audiology facilities in New Jersey with full diagnostic capabilities for infants that are either freestanding audiology practices, part of multi-specialty outpatient facilities, or at acute care hospitals that do not have maternity services. Birth and audiology facilities are concentrated in the northeastern section of the state, consistent with population density and the location of large cities (see facility map, Attachment 6-1)

Lost to Follow-up: As evidenced in Table 1 below, the New Jersey EHDI program efforts have substantially reduced the number of children that are lost to follow-up over the past several years, though there remains ample opportunity for continued improvement. Since the greatest number of children are lost between inpatient refer and outpatient rescreening, this will

² <http://www.census.gov/>

³ <http://kff.org/other/state-indicator/children-0-18/>

be the primary focus of the proposed activities. Other activities will target improving follow-up after outpatient rescreening refer or inconclusive diagnostic testing and increasing EI enrollment.

Table 1: Trends in Screening Refers and Follow-up in New Jersey

	2010 Births	2011 Births	2012 Births	2013 Births*
Number of live births	103,757	102,829	101,439	100,425
Number/Percent of infants receiving screening	102,872 (99.1%)	102,093 (99.3%)	100,787 (99.4%)	99,638 (99.2%)
Number/Percent of screened infants referring on inpatient screening	2901 (2.8%)	2907 (2.8%)	2504 (2.5%)	2263 (2.3%)
Number/Percent of infants referring on inpatient screening with outpatient screening OR diagnostic testing completed as first outpatient follow-up**	2475 (85.3%)	2474 (85.1%)	2149 (85.8%)	1948 (86.1%)
Number/Percent of infants lost to follow-up between inpatient refer and initial outpatient audiologic evaluation	426 (14.7%)	433 (14.9%)	355 (14.2%)	315 (13.9%)
Number of infants with inconclusive initial outpatient testing	360	361	282	311
Number/Percent of infants with inconclusive initial outpatient testing having additional outpatient follow-up completed.	232 (64.4%)	236 (65.4%)	203 (72.0%)	192 (61.7%) (additional appointments still pending for some)
Number of infants lost to follow-up between initial outpatient follow-up and audiologic diagnosis	128 (35.5%)	125 (34.6%)	79 (28.0%)	119 (38.2%)
Number of infants failing inpatient screening that were diagnosed with permanent hearing loss	94	118	129	Incomplete data, at least 95
Number/Percent of infants with hearing loss enrolled in Early Intervention	60 (63.8%)	87 (73.7%)	92 (71.3%)	Data not yet available
Number of infants lost to follow-up between audiologic diagnosis and Early Intervention	34 (36.2%)	31 (26.3%)	37 (28.7%)	Data not yet available

Source: Data from electronic birth certificate, outpatient follow-up reports, and EI data match with updates as of 9/17/14.

* 2013 data is preliminary. Additional data cleaning will likely create some increase in rates.
 **In New Jersey after an inpatient refer, some children are referred directly for diagnostic evaluation, while others are referred for outpatient rescreening, depending on birth facility.

The lost to follow-up rate calculated for the Centers for Disease Control and Prevention (CDC) annual EHDI survey excludes children that pass outpatient rescreening from the denominator for the Loss to Follow-up/Loss to Documentation (LTF/D) rate calculation. Approximately 66% of infants born in New Jersey who did not pass their inpatient hearing screening go on to pass outpatient rescreening. Exclusion of these cases from the denominator for the CDC LTF/D rate calculation results in a skewing of the LTF/D rate as compared to the rates noted above. The CDC survey LTF/D rates for New Jersey are noted in Table 2 below. As with the rates presented above, improvements have been made over time, but the rate of improvement is declining, suggesting that new and different strategies need to be attempted.

Table 2: CDC Survey Lost to Follow-up/Documentation Rates

	2006	2007	2008	2009	2010	2011	2012
New Jersey	77.5%	77.9%	65.5%	56.4%	45.3%	43.1%	42.8%
National	47.7%	46.1%	43.3%	45.1%	39.3%	35.3%	36.9%

Lost Between Inpatient Refer and Outpatient Rescreening: The New Jersey EHDI law and administrative rules place the primary responsibility for ensuring outpatient follow-up on the birth hospital. The hospitals are mandated to notify the primary care provider (PCP) of the inpatient screening results in writing; notify the parent of the inpatient screening results both in writing and face-to-face; notify the parents of where outpatient follow-up testing is available; and make at least one documented outreach attempt to families in need of additional follow-up by phone call, letter or other communication. For babies that despite those efforts do not have follow-up documented after several weeks, case managers contracted through the current HRSA funding will conduct outreach via telephone to families and in some cases PCP offices as an additional effort to ensure follow-up. Case managers have expertise in navigating social service issues and they have access to a telephone translation service in addition to one case manager being bilingual (English/Spanish). When they are unsuccessful in reaching the family by telephone, they will send a follow-up letter to the family. The EHDI program rules also include a requirement for health care providers to report children who are lost to follow-up, which aids in focusing the EHDI program’s efforts.

The reasons given when documenting lost to follow-up for infants born in 2013, are indicated in Table 3 below. Percentages total over 100% since providers may have indicated more than one reason (i.e., no show for an appointment, follow-up by a failed phone contact).

Table 3: Reason for Reporting Lost to Follow-up (n=314)

No show for scheduled appointment	45.2%
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No follow-up despite reminder letter effort	44.9%
No follow-up despite telephone contact effort	40.1%
Born in New Jersey, resides out of state, will seek follow-up in home state	2.9%
Moved out of state	2.5%
Parents refuse follow-up testing	2.2%
Child expired	1.0%

In 26% of cases where hospitals or audiologists reported children as lost to follow-up, they also indicated that the primary care provider was notified of the child’s need for additional follow-up. For children lost to initial outpatient follow-up, 81% had at least one outreach attempt by the case managers (averaging over three contacts per child) in addition to mandated hospital follow-up efforts. Attachment 6-2 provides an example of the follow-up efforts made for a random sample of 10 children born in 2013 that are currently LTF/D. It is clear that simple reminders to families of the need for follow-up are inadequate to ensure it is completed. Additional efforts are needed to contact and motivate families to receive follow-up, increase involvement of the medical home, and reduce identified barriers to care.

Reviewing the characteristics of the children that are lost to follow-up between discharge and rescreening serves to focus outreach efforts as well as dispel some assumptions about the barriers to care. For example, families that speak a language other than English might be presumed to have problems accessing care. However EHDI program data for 2013 births indicates that while 20.1% of all inpatient refers were to infants in Spanish-speaking households, these infants represented only 16.5% of the infants that were lost to follow-up. This suggests that facilities serving the Spanish speaking population have provided adequate instructions, written materials and/or translation services to eliminate language as a possible barrier to care. Furthermore, follow-up rates were 100% for the babies with an inpatient refer with a primary family language of Chinese, Hindi, Korean, and Portuguese. However, New Jersey EHDI data does show evidence of racial disparities in hearing healthcare with infants born to Black mothers representing 18.1% of all refers, but 28.8% of all LTF infants. Rates of LTF also vary by hospital of birth, ranging from 0% to 33%. Infants born to mothers who received Medicaid during pregnancy are slightly more likely to be LTF, representing 40.1% of infants that referred and 44.6% of LTF infants.

Lost Between Inconclusive Outpatient Testing and Diagnostic Audiology Services: One barrier to diagnostic testing may be the geographic accessibility of outpatient pediatric audiology services. In order to assist families in finding a convenient location that accepts their insurance, the EHDI Program annually surveys licensed audiologists, hearing aid dispensers, and otolaryngologists in the State to compile the New Jersey Pediatric Hearing Health Care Directory (PHHCD), which was initially distributed in 2006. In April 2011, the directory became an on-

line searchable database with the ability to map directions to the locations (www.hearinghelp4kids.nj.gov). Currently there are 26 New Jersey facilities in the PHHCD that can conduct a comprehensive diagnostic evaluation on an infant, including diagnostic Auditory Brainstem Response (ABR) testing under natural sleep conditions, with many clustered in the central and northeastern sections of the State (see Attachment 6-1). Only 13 of these conduct sedated ABR testing. Of the 21 New Jersey counties, one has no listed audiology services and nine counties have no facility that can conduct a comprehensive pediatric diagnostic exam. However, location of services does not seem to be a barrier for the majority of the children from 2013 that are LTF/D, since 59% were born at a facility with diagnostic audiologic services.

A more significant barrier to diagnostic testing may be appropriate follow-up for children who are identified with transient middle ear pathology which may delay referral for diagnostic audiologic evaluation. Of the children lost between rescreening and diagnostic testing, 43.9% were referred for medical management, as opposed to a referral for diagnostic evaluation. The physician community would likely benefit from reminders to order repeat audiologic evaluation after ear infections have resolved on children in their care.

Lost Between Diagnosis and Early Intervention (EI) Enrollment: The EI match done for 2012 births identified 37 children with diagnosed hearing loss that were not enrolled in EI services. The primary reason for lack on enrollment (46%) was that parents were unresponsive to contact. Sixteen percent of the unenrolled were cases where the infant expired, moved out of state or were born in New Jersey but reside out of state. Two infants were not receiving EI services because they remained in a long term care facility. In 13% the family was unable to be contacted and 19% of families declined participation in EI services. The lack of responsiveness to outreach attempts and number of families declining services may demonstrate insufficient family awareness of the benefits of EI. Of the families that declined EI or were unresponsive to contact, 58% were cases of unilateral hearing loss.

Methodology:

After the conclusion of the national NICHQ learning collaborative, the EHDI NICHQ team lead, Linda Biando, has promoted a continued Quality Improvement (QI) approach to EHDI program activities. Members of the multidisciplinary NICHQ Extended Team were asked to consider being a part of an ongoing EHDI QI Stakeholder Committee and additional new members were recruited. This committee will develop aim statements, plan small tests of change, perform those small tests when they are able, study the outcomes of the tests, and act on those results. This committee began holding bimonthly meetings in June 2014. The EHDI QI Stakeholder Committee has endorsed the goals and overarching aim statements noted below, and pledged ongoing support of PDSA cycles to meet these goals and aims and to develop additional aims and interventions (see Attachment 9-1).

Goal 1: By March 31, 2017, use quality improvement methodology, in partnership with the New Jersey EHDI Quality Improvement Stakeholders Committee and health care providers, so that Lost-to-Follow-Up/Lost-to-Documentation (LTF/D) after newborn hearing screen refer, as reported on the CDC annual EHDI survey (43% in 2012), is decreased to no more than 33%.

Aim Statement 1: By March 31, 2017, use quality improvement methodology, in partnership with the New Jersey EHDI Quality Improvement Stakeholders Committee and health care providers, to reduce the loss to follow-up rate between inpatient screening and initial outpatient follow-up by at least 2% during each year of the grant.

Aim Statement 2: By March 31, 2017, use quality improvement methodology, in partnership with the New Jersey EHDI Quality Improvement Stakeholders Committee and health care providers, reduce the loss to follow-up rate between outpatient follow-up testing and diagnostic testing by at least 2% during each year of the grant.

Goal 2: By March 31, 2017, use quality improvement methodology, in partnership with the New Jersey EHDI Quality Improvement Stakeholders Committee and health care providers, so that LTF/D for Early Intervention enrollment after a diagnosis of hearing loss, as reported on the CDC annual EHDI survey (31% in 2012), is decreased to no more than 21%.

Aim Statement 3: By March 31, 2017, use quality improvement methodology, in partnership with the New Jersey EHDI Quality Improvement Stakeholders Committee and health care providers, so that the percent of families that are unresponsive to contact will be reduced by at least 2% during each year of the grant.

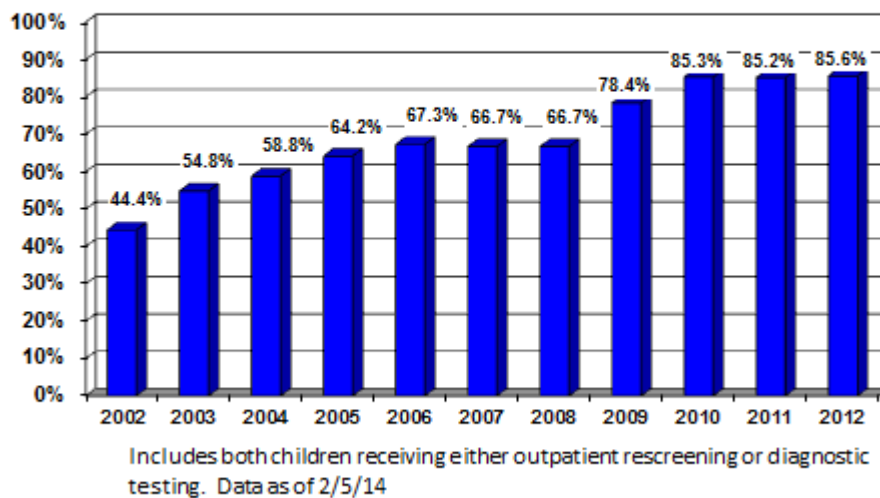
Aim Statement 4: By March 31, 2017, use quality improvement methodology, in partnership with the New Jersey EHDI Quality Improvement Stakeholders Committee and health care providers, so that the percent of families that decline Early Intervention enrollment will be reduced by at least 2% during each year of the grant.

Activities for this grant will be carried out by existing EHDI Program staff, primarily the Public Health Consultant – Nursing (PHCN), Linda Biando, RN, MSN, who is funded 75% from this grant. The EHDI Program's other full time staff (EHDI Audiologist, Research Scientist, and Principal Clerk Typist) and the Program Manager will also contribute to the grant activities. Subgrant funding for two projects will also support the goals of the grant. Funding will be provided to the Mercer County Special Child Health Services (SCHS) Case Management Unit (CMU), and NJEIS. See Attachment 5 for the Project Organizational Chart. The activities will focus on decreasing rates of children who are lost to follow-up at each point in the EHDI process. Loss to follow-up rates can be affected by the infant's failure to receive services or by the health care provider's failure to report services. Activities will focus on both ensuring infants receive follow-up and on improving reporting of follow-up to the EHDI program. Multiple

successful activities from the current funding cycle will be continued, and new activities will be implemented using the PDSA methodology.

Methodology to reduce loss to rescreening and diagnosis: After discharge, hospitals are required to make at least one reminder contact to families. If no follow-up has been reported to the EHDI program within six weeks of birth, and the hospital has not indicated a reason a follow-up is not expected (expired, moved out of state, or refused), then the case is referred to the CMU staff for additional efforts to contact the parents and/or PCPs to connect the family to follow-up services. This process was begun in October 2009 and contributed to a notable increase in follow-up rates beginning in 2009 (see Chart 1 below):

Chart 1: Percent of babies with referred inpatient hearing screening results with outpatient follow-up documented



HRSA funding will be used to continue this successful practice. For the cases referred to the CMU for this additional outreach during the current funding period to date, 192 (9%) were determined to be electronic birth certificate data entry errors, with the parent reporting the child passed screening before hospital discharge. For those that were true inpatient refers, 56.9% had additional follow-up testing completed following contact by the case managers. The other cases were unresponsive to CMU contact efforts or were unable to be contacted. See Attachment 4-1 for a letter of intent to continue this contractual arrangement.

The EHDI program will also continue to utilize the CMU staff to conduct outreach to families and physicians for children who referred on outpatient rescreening or had inconclusive diagnostic testing with no subsequent diagnostic exam. Of these cases that were referred to the CMU during the current grant period to date, 51.2% had a final hearing status reported (pass rescreening, pass diagnostic testing, or diagnosed with hearing loss). The remainder either still

had diagnosis in process (such as those with repetitive ear infections), or were unresponsive to contact by the CMU.

Another outcome of the case reviews and CMU outreach has been finding families who received follow-up, but for whom follow-up reports were not submitted to the EHDI program. Many of these undocumented outpatient screenings were conducted in pediatrician offices. The PHCN will conduct outreach to pediatricians to ensure proper reporting. This will include presentations at hospital pediatric department business meetings, visits to physician offices and clinics, and phone contact or site visits to individual providers. The American Academy of Pediatrics (AAP) Chapter Champion will also continue educational efforts to the pediatric community conducting grand rounds presentations and/or making individual outreach to physicians. See Attachment 9-2 for letter of support.

The EHDI Audiologist will continue to conduct activities to ensure the audiology community is aware of reporting obligations regarding submission of follow-up reports to the EHDI program. She will visit and/or conduct conference calls to audiology facilities throughout the funding period to provide technical assistance, training, and guidance.

Ensuring parents, hospital staff, and physicians know where they can receive services is essential to obtaining both outpatient rescreening and audiologic diagnosis. The Research Scientist and EHDI Audiologist will continue to ensure that the information in the Pediatric Hearing Health Care Directory is updated annually and is available on the EHDI web site.

The Research Scientist and Principal Clerk Typist will continue to generate quarterly reports to each hospital including listing of child-level detail for cases of children who were reported as referring on inpatient screening but have no outpatient follow-up reported. Hospitals are asked to fax reconciled reports back to the EHDI program within one month of receipt to ensure follow-up contacts were attempted and that listed children were true inpatient refers (see Attachment 9-3 for a sample report).

As another effort to ensure complete diagnostic testing, the Research Scientist and Principal Clerk Typist will continue the annual distribution of reports to audiology facilities. The reports will list children seen at that facility who had an outpatient rescreening refer result or had diagnostic testing that either was incomplete or indicted a transient conductive hearing loss and have not yet had final diagnostic testing. (See Attachment 9-4 for a sample report).

The PHCN will continue to offer technical assistance and support to hospital EHDI coordinators. She will conduct at least two webinars each year for hospital screening staff to highlight opportunities for improvement at the hospital level. She will identify the strategies determined to be successful through the PDSA cycles and utilize these webinars to spread these strategies to all hospitals in the state.

The following new activities will be implemented to reduce loss to follow-up between inpatient screening and diagnosis with the assistance of the EHDI QI Stakeholders committee and implementing a PDSA approach.

Hospital PDSA Teams

Plan: The EHDI Program will identify two hospital systems with higher than average loss to follow-up rates and ask each to assemble their own key personnel, including a parent member, to serve on a team whose goal is to improve follow-up using the model for improvement to describe the desired change (increase follow-up) and predict the results. The hospital and EHDI teams are expected to work together over at least a six to nine month period of time. The hospital will have the expectation of keeping a record of results to be submitted monthly to the EHDI program. The EHDI program will compile and share the data each month.

Do: Each hospital will be given the NICHQ Learning Collaborative list of promising strategies as part of the model for improvement and asked to choose a strategy to try with a specified small number of families whose infants referred on screening for month one of the cycle and keep track of what happens with that group related to follow-up. Follow-up rates for both the promising strategy infants and other infants requiring hearing follow-up will be compiled by the EHDI data manager. Regular monthly conference calls will be conducted describing observations, special circumstances, problems encountered and findings. This process will cycle each month.

Study: Follow-up rates for the infants will be kept for each cycle month. A monthly conference call between the EHDI program and the individual hospitals will take place at a regularly scheduled time. Each hospital will discuss their success or lack of success during the conference call. A monthly log will be kept by each individual hospital and submitted to the EHDI program.

Act: Each month the hospital and EHDI teams will discuss lessons learned and compare original predications to the current data. The PDSA cycle will be continued, altered, increased or abandoned to make room for a new approach or strategy based upon the data.

Scripting messages for follow-up contacts

Plan: The EHDI Program, together with the CMU will determine a scripted approach to use with parents of infants who are a month of age or older and have not had outpatient hearing follow-up after referring on inpatient screening or had an inconclusive outpatient exam and are receiving a reminder call for hearing follow-up. The model for improvement will be used. The CMU/EHDI team is expected to work together over at least a six to nine month period of time.

Do: From the weekly list of infants requiring hearing follow-up that is generated by the EHDI program, five parents will be selected to receive a consistent scripted message describing the need for infant hearing follow-up. The selection will include English and Spanish speaking

parents. Two case managers will use the script and two will conduct calls as usual. The script will be determined with mutual input from the EHDI program and the CMU in an initial meeting prior to script use. Data will be collected each week for both the scripted and non-scripted families by the EHDI Research Scientist. Monthly conference calls will be conducted describing observations, special circumstances, problems encountered and findings.

Study: Follow-up rates for infants will be kept for each cycle month. A monthly conference call between the EHDI program and the CMU will take place at a regularly scheduled time where case managers will discuss their success or lack of success. A monthly log will be kept by the EHDI program.

Act: Each month, the case managers and EHDI team will discuss lessons learned and compare our original predictions to the current data. The PDSA cycle will be continued, altered, increased or abandoned to make room for a new approach or strategy based upon the data.

Improving PCP and otolaryngology follow-up after incomplete testing

Plan: The EHDI program will expand awareness of PCPs and otolaryngologists regarding the importance of obtaining timely, complete and ear-specific information for patients in their practice for whom a definitive diagnosis has been deferred due to middle ear disease. In collaboration with the New Jersey AAP EHDI Chapter Champion (a neonatologist), the pediatrician and otolaryngologist from the New Jersey EHDI Hearing Evaluation Council (HEC), and the QI Stakeholder committee, the program will develop a brief survey for a small sample of pediatricians and otolaryngologists to determine if they verify their patient's initial screening results, if hearing screening is performed in their office, what audiology and/or otolaryngology providers they routinely recommend to their patients, if they are aware of facilities that provide comprehensive audiologic assessment for children under six months of age, and to inquire about their awareness of the goal of hearing diagnosis by 3 months of age.

Do: Results of the both the pediatrician and otolaryngologist's survey responses will be reviewed by the QI Stakeholders Committee to discuss strategies for providing evidence based solutions to enhance the knowledge of each surveyed medical specialist to ensure optimum hearing healthcare for their pediatric patients. The EHDI program and QI Stakeholders Committee will investigate the clinical protocols for two pediatrician offices that routinely refer infants who do not pass outpatient rescreening to otolaryngology practices for follow-up care. The clinical protocols for these otolaryngology practices will also be reviewed. The providers will be provided with protocols that encourage establishment of complete diagnostic testing by three months of age. Providers will be asked to provide information to the EHDI program on the next five children in their practice that need audiologic follow-up.

Study: Time to completed diagnostic status and results of the final audiologic assessment will be assessed for the identified children. Outcomes for children who are without definitive

diagnoses due to middle ear pathology who are seen at these practices will be reviewed again in three months to determine if any changes have resulted from protocol distribution.

Act: Each quarter, the EHDI program and QI Stakeholder Committee will discuss lessons learned and compare our original predictions to the current data. The protocol for additional follow-up will be modified as necessary and if successful, additional pediatricians and otolaryngologists will be identified to share and spread the protocol.

Additional strategies to identify and conduct outreach to families at risk for being lost to follow-up will be explored during the funding cycle. Recent research about psychosocial factors associated with loss to follow-up was conducted by faculty at Yeshiva University⁴. The audiologist on the EHDI advisory council attended a presentation on that research and shared information with the EHDI program noting that factors related to loss to follow-up after inpatient screening include lack of social support and maternal depression. New Jersey has had a strong postpartum depression (PPD) prevention effort since the 2000 passage of a postpartum depression screening law. The EHDI program will work with the DOH PPD program to explore ways to include messaging about seeking help for PPD in EHDI outreach efforts, and to have providers that are assessing mothers for PPD also inquire about hearing screening follow-up.

The EHDI program will also explore linkages with the New Jersey Supplemental Nutrition Program for Women, Infants and Children (WIC) as a mechanism to decrease LTF/D. Of 2013 births that were LTF, 29.1% were to mothers who received WIC during pregnancy and they represent 31.6% of all refers. In Year 1, the EHDI program will request access to WIC data files to obtain the most recent address and phone number information for WIC clients in order to aid case managers and hospital contacts in locating families that are unreachable using the information known at hospital discharge. In Year 2, the EHDI program will meet with WIC program staff to discuss and plan additional interventions using PDSA cycles.

Methods to reduce loss to Early Intervention enrollment: During the current HRSA funding period, the New Jersey EHDI program worked with NJEIS to implement a new consultant position for a specialist in hearing loss. Two part-time consultants were hired with the goal of establishing contact with the families soon after diagnosis to provide them with a non-biased overview of communication choices and EI services and to encourage EI enrollment and decrease the loss to follow-up after diagnosis. The consultants also participate in the initial family meeting via web conferencing to provide guidance on determining EI services that are appropriate for that family. This has been successful in improving timeliness of EI enrollment in reducing the number of families that are referred but do not complete enrollment. For children whose diagnosis of hearing loss was completed before three months of age, the time from

⁴ <http://www.yu.edu/wurzweiler/faculty/research/>

diagnosis to completion of a signed Individualized Family Service Plan (IFSP) in the six months before the consultants began was 198 days. For children born in 2013 the average was reduced to 140 days. In the six months before the consultants started, 4.3% of children that contacted EI did not continue to the completion of an IFSP, and for diagnosed children born in the first half of 2013 this was reduced to 1.3%. The funding of the EI hearing loss consultants will continue through all two years of the proposed funding period to maintain and increase these gains. See Attachment 4-2 for letter of intent to continue this contractual agreement.

The EHDI Audiologist will continue to provide education to New Jersey audiologists to improve EI enrollment. The focus will be to ensure that after diagnosing children with hearing loss, the audiologist will encourage the family to make contact with EI and/or respond to calls from case managers to facilitate their timely EI enrollment.

As a new activity to reduce loss to follow-up between diagnosis and early intervention enrollment, strategies will be tested to improve communication with parents about the benefits of participation in the EI system.

Decreasing non-responsive and declinations between diagnosis and EI enrollment

Plan: The EHDI program will collaborate with NJEIS and all 21 county CMUs to develop a script for case managers to use when discussing options available to families through the EI system based on the presumptive eligibility of infants with newly identified hearing loss. Since approximately 120 New Jersey live births each year are identified with hearing loss throughout the 21 New Jersey counties, some counties may not enroll a baby with hearing loss during an entire calendar year or longer. We predict that a scripted EI message will lend itself to improved EI enrollment by at least 2% each grant year based on the consistent message included in the script. The EI, CMU and EHDI teams are expected to work together over at least a six to nine month period of time to develop the script, begin utilizing the script with a small number of families at first and track data regarding EI enrollment. The EHDI program will have the expectation of compiling data submitted quarterly to the EHDI program through the already established quarterly EHDI/EI data match. The EHDI program will compile and share the data each quarter and share with our EI and CMU colleagues.

Do: The EHDI program will identify five babies each month who are newly identified with hearing loss and contact the CMU unit where the family resides. The case managers will go over the scripted message with the parents. The quarterly EHDI/EI match will be reviewed to determine if the families that received the scripted message have enrolled in EI.

Study: A quarterly conference call meeting between the CMU and EHDI will be conducted to review the process and follow-up. We will discuss the success or lack of success of the script. A monthly log will be kept by the EHDI program.

Act: Each quarter, the CMU and EHDI team will discuss lessons learned and compare our original predictions to the current data. The PDSA cycle will be continued, altered, increased or abandoned to make room for a new approach or strategy based upon the data.

Advisory Committee: New Jersey's hearing screening legislation mandates the existence of the Hearing Evaluation Council (HEC) and stipulates the membership to include "a board-certified pediatrician, a board-certified otolaryngologist, an audiologist with certified clinical competence, a person who is profoundly deaf, a person who is hearing impaired, a hearing person of parents who are deaf, and a citizen of the State who is interested in the concerns and welfare of the deaf." Though the law does not specifically require including parents of hearing impaired children, parents of hearing impaired children currently fill the "concerned citizen" position as well as the hard of hearing position. Members are appointed by the Commissioner of Health and serve two year terms. Though the legislation stipulates that the Council meet at least once per year, the HEC has held meetings three to four times each year since its inception in December 2005.

Linkages: The EHDI program is well integrated with the Title V program as New Jersey's Title V activities are all housed within the Division of Family Health Services along with the EHDI program. The State Title V contact for Children with Special Health Care Needs is Dr. Marilyn Gorney-Daley, who is the Service Director for the unit that includes the EHDI program (see Organizational Charts, Attachment 6-3). The Research Scientist participated in the August 2014 Title V Maternal Child Health Block Grant (MCHBG) program review with the regional HRSA staff in New York City. The EHDI program provides data for the MCHBG Performance Measure 12 (percentage of newborns who have been screened for hearing before hospital discharge) and New Jersey has also chosen to report audiologic follow-up after not passing inpatient screening as a MCHBG State Performance Measure.

The EHDI program has begun partnering with the New Jersey Family Health Services Maternal Child Home Visiting (MCHV) program. In October 2014 the EHDI PHCN will attend a MCHV meeting for nurses who visit parents of infants and present information about the State EHDI program to familiarize them with the process and to answer questions. Future collaboration will involve discussion of approaches to include home visit assessment of infant hearing screening status, such as assessing if infant passed the newborn screen at the hospital and if not, if outpatient follow-up was completed. Resources to be shared with the MCHV nurses will include the New Jersey Pediatric Hearing Healthcare Directory, the scripted "Next Steps" checklist for babies that refer, and Learning about Hearing Loss -- A Roadmap for Families.

Early Head Start: Early Head Start programs serve economically disadvantaged children from birth to age 3 through provision of early, continuous and comprehensive child and family support services. All children participating in Early Head Start (EHS) programs must receive a

hearing screening within 45 days of enrollment. New Jersey's current regulatory requirements present challenges in terms of allowing individuals other than licensed audiologists, speech-language pathologists, physicians or individuals directly under their supervision, to administer hearing screenings. Nonetheless, a collaborative effort between the New Jersey EHDI Program and New Jersey's 47 EHS programs would be beneficial in identifying toddlers who present with previously unidentified hearing loss. The EHDI program is currently exploring options for connecting appropriate licensed professionals to provide screening services, information and support that allow EHS to meet their hearing screening guidelines while still ensuring that services are being provided without conflict with New Jersey's licensing mandates. During the upcoming grant cycle, the EHDI Program will work with EHS to support acceptable hearing screening activities and educational needs.

Sustainability: MCHBG funding currently supports the EHDI audiologist, the EHDI clerk, 10% of the salary of the Research Scientist 1 (with the CDC EHDI grant covering the remainder), and 25% of the PCHN (with the HRSA funding supporting 75%). Therefore, if HRSA funding is eliminated, there will still be some staff and funding available for support of newborn hearing screening. However, subgrants to the CMU for outreach contacts and to the REIC for the EI hearing consultants would likely not be able to continue without HRSA funding and some resultant decrease in follow-up rates could occur.

Current program efforts are aimed at reducing the need for active follow-up provided by the New Jersey EHDI program. A benefit of having the primary responsibility for follow-up fall to the hospitals is that it encourages sustainability. Since hospital efforts to ensure follow-up are mandated in administrative rules, they should continue regardless of availability of State EHDI staff and HRSA funding. EHDI program efforts to educate PCPs, audiologists and otolaryngologists about EHDI goals and reporting requirements should serve to make timely and appropriate follow-up after failed hearing screening a standard of care that is followed without the need for persistent reminders and provider contacts. In addition, one activity for the proposed funding cycle will be to encourage hospitals to create their own local QI teams and follow the PDSA to improve their follow-up rates. If this strategy is successful in having facilities consistently working to improve their individual performance and can be spread to all birthing hospitals, this should reduce the active follow-up burden on the New Jersey EHDI program and promote sustainability of reductions in loss to follow-up.

Work Plan

The work plan for the project period is detailed in Attachment 1. For each Aim of the project, specific activities, timelines, process measures and outcome measures have been detailed where they have been identified. The application of the QI process to this project will create some ongoing changes to the identified work plan as additional stakeholders are engaged in the

efforts, and since the study of small tests of change may determine that a strategy is ineffective and needs to be abandoned or modified.

The PHCN historically has communicated regularly with hospital staff, initially through individual site visits and conferences calls, and more recently via several webinars for hospital EHDI contacts. For successful small tests of change that hospitals can apply to their processes, she will utilize these existing lines of communication to highlight successful strategies and encourage the spread of those strategies to hospitals throughout the state.

The EHDI QI Stakeholder committee will be called upon to provide suggestions for how successful small tests of change may need to be modified for different hospitals, locations or situations to reflect differences in the cultural, racial, linguistic and geographic characteristics. For example, a strategy that is successful at a hospital that has an audiology department may not be successful at a hospital that does not have an audiology department. Or there may be regional differences in what translations of educational materials may be needed.

For spread of strategies carried out by smaller specific groups of individuals, such as scripting the message used by case managers, communicating follow-up needs to otolaryngologists, and modifying messages about EI provided to parents, the small tests of change will be attempted on small numbers of children (such as the next 5 children without follow-up documentation or diagnosed with hearing loss) and, if successful, will be spread by using the strategy for all children going forward. Successful strategies will also be spread with other states and territories through the presentations or poster sessions by the EHDI staff at the annual national EHDI meeting, as has been done with past NICHQ collaborative successes.

Resolution of Challenges

Hospital QI Team Initiative: Individual hospital ownership of QI activities for hearing screening and follow-up is a relatively new concept for most of the 52 New Jersey birthing hospitals. Most hospitals view their QI activities as being driven by the State EHDI program as a response to distribution of the quarterly reports and the hospital-specific statistics. A new model for improvement based on small tests of change and utilizing of PDSA cycles will be an approach presented to at least two hospitals with follow-up rates well below the State average. Methodology, instruction and staff acceptance will be essential to the success of adopting this process and making it successful and enabling spread to additional hospitals. The inclusion of at least one parent into the hospital based QI team will be strongly encouraged.

Audiology Services Availability: One of the identified barriers that has prevented infants from receiving timely and appropriate diagnostic audiologic testing is the challenge in locating comprehensive pediatric audiology facilities within a family's local geographic area. New Jersey is the fourth smallest state in the country, however the availability of pediatric audiology services can be very limited in select regions, particularly in the southern and northwestern portions of the

State (see Attachment 6-1 for facility map). While the New Jersey EHDI program annually surveys all of the facilities currently listed in the Pediatric Hearing Health Care Directory (PHHCD), there may still exist diagnostic sites that are not represented in this valuable online resource. The New Jersey Division of Consumer Affairs reports that each year brings additional applications from newly graduated and/or out-of-state audiologists who are interested in obtaining licensure in New Jersey. Increased numbers of New Jersey licensed audiologists lends itself to the availability of increased pediatric audiology practitioners/facilities throughout the State. Yearly outreach to obtain current mailing addresses for all licensed audiologists in New Jersey will allow for an up-to-date outreach initiative of inviting all audiologists the opportunity to list their services in the PHHCD. Adding additional recipients to the annually distributed PHHCD survey may yield more listings of pediatric audiology facilities affording families additional options regarding convenient locations for hearing healthcare follow-up. An added benefit of increasing the number of facilities in the PHHCD will be the opportunity of more outpatient reporting to the EHDI program, and subsequently, will result in more diagnostic sites being able to monitor their compliance with JCIH recommendations and New Jersey regulatory requirements through the annually distributed audiology facility reports.

Improving Access to Early Intervention: The addition of two hearing consultants to the EI program has resulted in access to knowledgeable and unbiased guides who can assist parents/guardians in navigating the complexities of the EI system and meeting the needs of children identified with hearing loss. NJEIS and NJ EHDI collaborated on the development of a document that outlines the role of the hearing consultants; allows for transmission of audiologic reports to the NJEIS and provides linkage to the family with the Regional Early Intervention Collaborative (REIC). Audiologists throughout New Jersey and its border states who are known to the EHDI program have been advised to encourage families of children identified with hearing loss in one or both ears, to contact EIS immediately to begin the referral process. Audiologists are asked to have the parent sign the 'Authorization to Release Information to the NJEIS' form, allowing them to send all pertinent hearing healthcare documents to NJEIS. This form also serves as a flag to REIC staff to offer the services of the hearing consultants to families of children with hearing loss. The availability of the consultants has been in place since July 2012, and was made known to the audiology community through an announcement sent via the EHDI audiology email distribution list as well as through a webinar. Though referrals to the consultants have increased since the inception of this specialty program, there is still a need for ongoing outreach to the audiology community on a regular and more comprehensive basis. Efforts to increase the visibility of the consultants and their role in the NJEIS process will be presented to audiologists throughout the State through webinars that will allow easy and free access to

audiologists in all clinical venues. The hearing consultants will have the opportunity to give a presentation, with time for a question and answer period.

Evaluation and Technical Support Capacity

Data System and Reporting: The EHDI program, through funding received from the CDC, has developed a data system that readily enables monitoring the impact of the project and conducting quality improvement activities. The Research Scientist has accountability for collection of all EHDI-related data from various sources, maintenance of the EHDI database, and responding to the annual CDC EHDI data survey as well as all other reports and data requests related to the EHDI data system.

New Jersey EHDI administrative rules mandate that inpatient newborn hearing screening results be reported electronically to the EHDI program via the state's electronic birth certificate system. Extracts from this system are created weekly and imported into the EHDI database. The EHDI administrative rules require the Newborn Hearing Follow-up Report form be submitted for all outpatient testing of infants and toddlers. Upon diagnosis of a permanent hearing loss, audiologists are also required to report children (through age 21) to the Special Child Health Services (SCHS) Registry. This is a comprehensive, confidential database that provides unduplicated data on children with birth defects and special needs. SCHS registrations are forwarded to the appropriate county's Case Management Unit (CMU). The CMUs ensure children with special health care needs have a medical home and that care is coordinated among medical providers. The CMUs also refer children with hearing loss to Part C Early Intervention (EI) services. Providers are also mandated to report children identified as lost to follow-up (i.e., unresponsive to reminder contacts, parent refusal of follow-up services, child died or moved out of state, etc.) on the Lost to Hearing Follow-up Report form. These forms can be completed either on paper, or electronically using a module integrated into the web-based New Jersey Immunization Information System (NJiIS).

Reporting of EI status is part of a broader collaboration with EI quality assurance and Child Find processes. The EI program and the SCHS Registry routinely match data for children with a diagnosis that indicates presumptive eligibility for EI services to identify eligible, but unenrolled, children. Since any degree of hearing loss is a diagnosis of presumptive eligibility for EI in New Jersey, this data match also enables determination of EI enrollment status for children with hearing loss and age at EI enrollment.

Data files with inpatient results from the birth certificate system, data files with outpatient follow-up results or loss to follow-up documentation from the NJiIS system, and data files from the EI match are imported into the EHDI database. This is a Microsoft Access database developed and maintained by the EHDI Research Scientist.

Quarterly reports provided to each hospital (Attachment 9-3) provide a mechanism for quality assurance to validate inpatient screening results and verify that hospitals attempted their required follow-up contact with a fax back response required. One result of prior reviews is that hospitals have found that some inpatient refer results were documentation errors, where children noted as referring had actually passed. Correction of these errors allows for a more accurate reflection of babies that are in need of follow-up. The case review has also identified gaps in communication or referral procedures in some hospitals.

Semi-annually the hospital reports also include summary statistics for hospital-specific and overall State screening rates, refer rates, and follow-up rates, including three-year trends (Attachment 9-5). The EHDI program reviews performance internally and also with the HEC to identify areas of needed improvement. Additionally, the Research Scientist runs hospital-specific screening and refer rates weekly when uploading the inpatient data from Vital Statistics. Any outliers, such as sudden drops in screening rates or rises in refer rates, will result in a call to the hospital to determine if the hospital is experiencing equipment problems.

Evaluation of Performance: The EHDI program's logic model (Attachment 6-4) provides an overview of the key inputs, activities, outputs and outcomes for the program. The EHDI database will be the mechanism used to track the majority of outcome measures. Rates of loss to follow-up for screening, diagnosis, and EI can all be calculated from the data system. Follow-up rates can be readily calculated for specific sub-groups such as by hospital or for a given time frame (e.g. one month). Since the EHDI program receives information from the birth certificate system, the program also has the ability to monitor follow-up rates stratified by particular demographic categories such as maternal age, race, or primary language of the family, which are all available in the data extracted from the birth certificate system.

Process performance measures will also be utilized as detailed in the Work Plan (Attachment 1) and include measurements such as the number of meetings held, the number of attendees, the number of reports distributed and the number of family contacts. The Research Scientist, as the data lead for the EHDI QI Stakeholders Committee, will assist individuals and groups that are implementing small tests of change in identifying elements to be measured and in completing analyses of the collected data. The PDSA worksheet (Attachment 9-6) will be used to assist the QI process. Run charts will be generated of key indicators for the QI Stakeholder Committee to review. The Research Scientist will also assist the individuals and groups that are implementing small tests of change in creating materials to collect data. For example, for testing a change in scripting the message, a short log form will be created asking the case managers to indicate the system identification number for each family they contact using the scripted message. After logging five entries, the log will be faxed to the EHDI program and after a period of one month the Research Scientist will document the follow-up status of those five

children. Results will be shared with the QI Stakeholders Committee and the case managers.

Performance Measurement Obstacles: Semi-annual measurement of screening and follow-up rates and annual assessment of EI enrollment are part of ongoing EHDI program activities with no significant obstacles to measurement anticipated. Measurement of small tests of change will be dependent upon the partners that are implementing the strategies including hospital EHDI staff, case managers, and pediatricians. If these partners have difficulty documenting their results or do not embrace the importance of logging their results, measurement of performance may be hindered. The PHCN and the Research Scientist will work with these partners as part of the QI process to ensure that data collection forms are simple and easy to use and that the health care providers understand the importance of data collection.

Staff Skills and Experience: All EHDI project staff have served in their current roles for at least 10 years (see job descriptions in Attachment 2 and biographical sketches in Attachment 3). This long experience with the program, and in working with our hospital, audiologist, and physician communities, is beneficial to evaluating the success of the program's efforts. Some additional knowledge, skills, and experience demonstrating the EHDI team's ability to evaluate progress toward the grant objectives are noted below.

Linda Biando is the Public Health Consultant - Nursing for the EHDI Program and has over 20 years of experience with the New Jersey DOH, joining the EHDI program in 2004. In her current EHDI position and in her previous work with the SCHS Registry program she has conducted evaluations of hospital compliance with State rules. She was the New Jersey EHDI team lead for the NICHQ Learning Collaborative during the current funding cycle.

Nancy Schneider is the Research Scientist 2/Audiologist for the EHDI Program since joining the DOH in 2003. The majority of her pediatric clinical audiology experience was at a university teaching hospital, including designing the initial hearing screening program for that hospital. She also has been an adjunct faculty instructor, and thus has extensive experience with evaluation and supervision of clinical and academic performance of individuals. Ms. Schneider also serves on the New Jersey Audiology and Speech-Language Pathology licensing board, thus is experienced with evaluating whether audiologists are appropriately providing care within their scope of practice.

Kathryn Aveni is the Research Scientist 1 for the EHDI Program and serves as the overall EHDI program coordinator. She joined the DOH and the EHDI program in 2002, the year universal newborn hearing screening became mandated in New Jersey. She participated on the NICHQ Learning Collaborative team as the data point person and continues to provide data analyses to the QI Stakeholders group. In her prior position as Director of Quality Assurance for a non-profit maternal-child health agency, she did data analysis and conducted regular program evaluation meetings. In addition, Ms. Aveni has completed a Juran Institute course in

“Facilitating and Leading Quality Improvement Teams.”

Tracey Justice is the Principal Clerk Typist and has been with the EHDI program since 2003. She completes data entry of outpatient follow-up forms, runs the EHDI hospital-specific reports, and handles program mailings as well as other clerical tasks for the program.

Leslie Beres-Sochka is the Program Manager and has primary responsibility for the Early Identification and Monitoring Program, including the EHDI Program, the Birth Defects and Autism Registry, and the Critical Congenital Heart Defect screening program. She joined the DOH in 1990 and has had oversight of the EHDI program since 1999. She has over 25 years of experience in research, statistical analysis, and database design/management, grants management, and in the administration of screening and surveillance programs.

To nationally disseminate the results of their achievements, EHDI staff have given or co-authored eleven national EHDI meeting presentations or posters since 2002. Most recently, at the 2014 meeting, the PHCN presented, along with other NICHQ collaborative team members *'The 'Next Steps,' a Checklist to Improve Hearing Follow-Up and Intervention'* describing this successful QI effort. She has also submitted an abstract on continued work on this effort as a poster presentation for the 2015 EHDI meeting.

Organizational Information

Organizational Structure: The EHDI program is administered through the Division of Family Health Services (FHS), based within the Special Child Health and Early Intervention Services (SCHEIS) in the Early Identification and Monitoring program (EIM), all of which are headquartered at the New Jersey DOH in Trenton, New Jersey. The mission of the EHDI program is to ensure that all New Jersey’s children, between birth and 3, receive timely and appropriate hearing screening and diagnostic audiologic testing, as well as culturally competent early intervention for those children identified with hearing loss in one or both ears. The EHDI program accomplishes these goals through provision of technical assistance to birthing facilities; education and support to families and health care providers; and via the establishment of a confidential registry and tracking system to ensure children are screened, have appropriate follow-up and are linked to services. The mission of the DOH is to improve health through leadership and innovation with the specific goals of FHS focused on promoting and protecting the health of mothers, children, adolescents, and at-risk populations as well as to reduce disparities in health outcomes by ensuring access to quality comprehensive care (See organization charts, Attachment 6-3). FHS consists of 4 service units: Maternal and Child Health Services; Women, Infants, and Children (WIC) Services; Community Health and Wellness Services and Special Child Health and Early Intervention Services (SCHEIS); as well as the Office of Primary Care & Rural Health and Fiscal & Grants Management. All of the units within FHS work to improve the health, safety, and well-being of families and communities in

New Jersey and support the goals of the Maternal and Child Health Block Grant. SCHEIS, the Title V program for children with special health care needs, is comprised of 4 programs: Early Identification and Monitoring (EIM), Newborn Screening and Genetic Services (NS&GS), Family Centered Care Services (FCC), and the New Jersey Early Intervention System (NJEIS). EIM is responsible for maintaining the EHDI Program, the Birth Defects and Autism Registry and the Critical Congenital Heart Disease screening program. NJEIS and FCC offer comprehensive management of multiple programs and services that enhance the health, safety and well-being of families and communities in New Jersey. In July 1993, NJEIS was designated the lead agency for Part C of the Individuals with Disabilities Education Act when these services were transferred to DOH from the New Jersey Department of Education. EIS serves children up to age three who have developmental delays or disabilities. Family Centered Care (FCC) Services serve children of all ages who present with complex medical conditions. FCC is responsible for the HIV Family Centered Care Network as well as the 21 county-based case management units which are jointly funded by SCHS and county freeholders. SCHS case managers work with the child's parents and their physician to evaluate an affected child's medical, educational, developmental, social and economic strengths and needs and develop an individual service plan for the child and family. NS&GS is responsible for tracking all newborns with abnormal bloodspot screens, ensuring they are rescreened, and that they are in treatment if diagnosed with a disorder. Currently in New Jersey genetic and biochemical screening/testing is mandated for 54 specific disorders.

New Jersey historically has had a strong infrastructure to support newborn hearing services, with staff responsible for ensuring testing, follow-up, diagnosis, and Early Intervention all located together both physically and organizationally in the same unit within the DOH. This organizational structure (See organizational charts, Attachment 6-3) facilitates the cooperation and collaboration necessary for a successful EHDI program. Relationships with other Divisions of the DOH include those with the New Jersey Immunization Information System (NJIS) in the Division of Epidemiology, Environmental and Occupational Health. The EHDI program also works with the Office of Vital Statistics and Registration, which is in the process of implementing a new web-based electronic vital record system, termed the Vital Information Platform (VIP). This system is currently being pilot tested at six facilities with the expectation of implementation in all hospitals by the end of 2014. The EHDI program has had an active role as a management team partner during the development of the VIP to ensure that inpatient hearing screening results continue to be captured and that the data is available for EHDI program use.

Collaboration with the New Jersey Division of the Deaf and Hard of Hearing (DDHH) in the Department of Human Services has included EHDI representation on the DDHH Advisory Council; collaboration on development of a parent education brochure for Grace's Law (a

legislative mandate requiring insurance coverage of hearing aids for children), and, along with New Jersey Statewide Parent to Parent and its parent organization, the Statewide Parent Advocacy Network, have co-produced a family driven, biennial event since 2005, entitled the “Family Learning Conference for Families With Children who are Deaf and Hard of Hearing.” The EHDI Program has also established successful working relationships with the Office of Special Education staff at the New Jersey Department of Education and assisted them with development of a parent information packet for families of children with hearing loss.

Quality Improvement Experience: In 2012, the New Jersey EHDI program partnered with the National Initiative for Children’s Healthcare Quality (NICHQ) Improving Hearing Screening and Intervention Systems (IHSIS) Learning Collaborative. Central to success with process was building effective partnerships between our state EHDI program, the health community and parents. The goal of this fourteen month collaborative was to identify and spread successful ideas by strengthening relationships between team members and to improve the quality of care to newborns with hearing loss.

Our NICHQ/IHSIS objective was to find new and creative ways to meet our program goals of screening by one month, diagnosis by three months, and intervention by six months. An approach called the “Model for Improvement” was used. Identification of four key elements of successful process improvement (measurable aims, time tracked measures of improvement, changes that lead to improvement, and testing cycles) was used. Through small tests of change, we evaluated our success, altered and expanded our process, adopted or abandoned plans, and shared successes with others. This Plan, Do Study and Act (PDSA) process helped us to plan tests of change with guidance from our expert team members, analyze our progress, develop strategies to overcome barriers and plan for the spread of the positive changes.

New Jersey developed several successful PDSA’s such as the “Next Steps” checklist and script, designed to deliver a consistent message in a simple literacy friendly format, with picture identifiers that give the health care professional a vehicle to measure understanding through restatement. Originally designed for use by audiology when hearing loss was identified, our NICHQ team members adapted and spread this concept creating next step checklists for families of infants that referred in the hospital, for infants with ear canal atresia, and for the medical home. Other successful PDSA’s include giving a prescription for hearing follow-up before discharge and written audiology instructions coupled with reminder phone calls.

As a result of our successes with NICHQ, we in New Jersey have established a New Jersey QI Stakeholders Committee to continue this successful process for positive change utilizing the PDSA process and representation from the community.