Program Narrative

Introduction:

Significant hearing loss is one of the most common health conditions present at birth, estimated to occur in about three per 1,000 live births. In New Jersey, with approximately 105,000 annual occurrent live births, an estimated 300 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.

New Jersey has a strong infrastructure to support newborn hearing screening. Public Law 2001, chapter 373 (N.J.S.A. 26:2-103.1 et seq.) requires universal newborn hearing screening and administrative rules (N.J.A.C. 8-19:1) provide specific and enforceable criteria for hospitals, physicians, and audiologists to ensure follow-up after inpatient screening. New Jersey has had great success with inpatient screening, with rates increasing from 30.3% in 1998 to 99.8% in 2010. Achieving the national goal of ensuring diagnostic audiologic testing by three months of age is improving, but remains a challenge. For babies born in 2002 who failed their inpatient screening, 44.4% had outpatient follow-up testing reported to the Early Hearing Detection and Intervention (EHDI) Program. For 2010 the rate increased to 80.3%. Yet for children who fail outpatient rescreening, only 34% completed diagnostic testing. Impediments include families declining follow-up evaluation, lack of local audiology facilities, failure of physicians to refer families for follow-up testing, financial or insurance concerns, families receiving out-of-state follow-up, and families who move or are otherwise lost to follow-up. Another issue is the failure of providers to provide documentation of follow-up exams to the EHDI program.

The purpose of the proposed HRSA grant is to further focus efforts to reduce the number of infants who are lost to follow-up or documentation after a failed hearing screening. New Jersey has received EHDI funding from HRSA since 2002 that has substantially assisted the program in reducing loss to follow-up. An accomplishment summary for the current funding period is described in Attachment 7. The New Jersey EHDI Program will use funding from the proposed grant 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 encourage implementation of National Institute on Children's Healthcare Quality (NICHQ) Learning Collaborative strategies, serve as the EHDI liaison to the physician community, and engage in specific targeted follow-up activities which are described in detail in the methodology section.

Need Assessment:

Demographics: New Jersey is geographically small and is the most densely populated State with 1,174 persons per square mile. With 8.7 million people, it is the eleventh most populous State, with three percent of the national population. For New Jersey births in 2007, 46.1% of the mothers were White non-Hispanic; 25.5% were Hispanic, any race; 14.9% were Black non-Hispanic, and 9.5% were Asian or Pacific Islander. Census data from 2006 revealed that 27.6% of people over age five in New Jersey spoke a language other than English at home and 11.8% spoke English "not very well" or "not at all." Spanish, Italian, Chinese, Polish, and Portuguese were the five most common languages other than English. The racial, ethnic, and linguistic diversity contribute to the cultural richness of New Jersey, but can be a barrier to follow-up.

Live Births and Hospitals: New Jersey currently has about 105,000 births each year, predominately occurring in the 53 hospitals with maternity services. Home births are very rare, representing about 200 (0.2%) of New Jersey births annually. Twenty-nine of the hospitals with maternity services have an audiology department, and some other hospitals have the nursery staff conduct outpatient rescreening. Other hospitals must refer families elsewhere for follow-up.

Medical Home: Determining a child's medical home can be very challenging. The New Jersey Electronic Birth Certificate (EBC) contains a data field for the name of the provider who will provide the infant’s future immunizations. Hospital staff are very aware of the need to identify a future medical home for issues beyond just newborn hearing screening, and generally work with families to try to establish the future care provider. However, while the physician who cared for the child during the inpatient stay is often identified as the physician of record, it is a common occurrence for families to use a different physician after hospital discharge.

The Newborn Hearing Follow-up Report (SCH-2) form includes a line to indicate the child’s physician. Approximately 45% of the SCH-2 forms received for babies born in 2010 did not have a valid physician name, contributing to the challenge of identifying the medical home. The current administrative rules for the Immunization Program require providers to utilize the web-based registry known as the New Jersey Immunization Information System (NJIIS) beginning December 31, 2011. Since the EHDI program’s electronic reporting system for outpatient follow-up is a module within the NJIIS, the regulation should increase the likelihood that children can be linked to a medical home using this data system.

Lost to Follow-up: As evidenced in Table 1 below, EHDI program efforts have reduced the total number of children that are lost to follow-up over the past several years, though there is ample opportunity to improve these efforts. Since the greatest number of children are lost between inpatient refer and outpatient screening, this will be the primary focus of the proposed activities. A secondary focus will be improving follow-up after outpatient rescreening refer, since the current rate of follow-up is the lowest for this point of the process.

Table 1: Trends in Screening Refers and Follow-up

	2008 Births	**2009 Births**	**2010 Births**
Number/Percent of screened infants referring on inpatient screening	3104 (2.9%)	3081 (2.9%)	2868 (2.8%)
Number/Percent of infants referring on inpatient screening with outpatient screening OR diagnostic testing completed as first outpatient follow-up*	2311 (74.5%)	2419 (78.6%)	2321 (80.9%)
Number of infants lost to follow-up between inpatient refer and initial outpatient audiologic evaluation	793	660	547
Number of infants with failed outpatient rescreening or inconclusive diagnostic testing	229	221	231
Number/Percent of infants with failed outpatient screening or inconclusive diagnostic testing receiving diagnostic evaluation*	81 (35.4%)	104 (47.1%)	78 (33.8%) (data incomplete)
Number of infants lost to follow-up between outpatient follow-up and audiologic diagnosis	148	117	153 (data incomplete)
Number of infants failing inpatient screened that were diagnosed with permanent hearing loss	117	95	80 (data incomplete)
Number/Percent of infants with hearing loss enrolled in Early Intervention	84 (71.8%)	62 (65.3%)	Data pending
Number of infants lost to follow-up between audiologic diagnosis and Early Intervention**	33	33	Data pending

Source: Screening and Follow-up Report data as of 9/15/11. Data on diagnosed cases of hearing loss and Early Intervention as of 12/31/10.
*In New Jersey, some children are referred directly for diagnostic evaluation, instead of rescreening, following inpatient refer.
**Excludes infants who expired after diagnoses, before EI enrollment.

Lost Between Inpatient Refer and Outpatient Rescreening: The EHDI program rules 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. For babies born in 2010, the reasons that children were identified as lost to follow-up are indicated in Table 2 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 2: Reason for Reporting Lost to Follow-up (n=513)

No follow-up despite telephone contact effort	78.9%
No follow-up despite reminder letter effort	36.5%
No show for scheduled appointment	29.8%
Born in NJ, resides out of state, and will seek follow-up in home state	3.7%
Moved out of state	2.7%
Parents refuse follow-up testing	1.6%
Child expired	1.2%

The vast majority (86%) of those lost to follow-up have received direct outreach efforts. In 14% of cases where hospitals or audiologists reported children as lost to follow-up, the primary care provider was also notified of the child's need for additional follow-up. 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 motivate families to receive follow-up and to reduce barriers to care.

Further information from the Lost to Newborn Hearing Follow-Up forms for 2010 births reveal that 0.7% indicated a letter was returned undeliverable, 1.8% noted the telephone number called was a wrong number, and 5.2% indicated the telephone number called was disconnected. These statistics suggest that the NICHQ recommendation of obtaining a second point of contact may be a useful strategy for a small subset of those who are lost. Loss to follow-up between diagnosis and early intervention is also affected by failed attempts at family contact. In a review of the reasons that children with hearing loss were not enrolled in EI, for approximately half of the cases the case managers had been unsuccessful in attempts to contact the parents.

Data analysis for the children that are lost to follow-up between discharge and rescreening serves to dispel some assumptions about the barriers to care. For example, families that speak a language other than English might be presumed to have barriers accessing care. However, EHDI program data indicates that while 22.4% of all inpatient refers were to infants in Spanish-speaking households, these infants represented only 17.3% of the infants that were lost to follow-up. This suggests that facilities serving the Spanish speaking population have provided materials and/or staff to eliminate language as a possible barrier to care.

Lost Between Outpatient Refer and Diagnostic Audiology Services: One barrier to diagnostic testing may be the availability of 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 and compiles the New Jersey Pediatric Hearing Health Care Directory, 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 Directory that can conduct a diagnostic evaluation on an infant, with many clustered in the central and northeastern sections of the State (see Attachment 1-1). Of the 21 counties in New Jersey, two counties have no listed audiology services and seven additional counties have no facility that can conduct a comprehensive diagnostic exam. However, facility location is not the primary barrier to audiology follow-up. Of 130 children born in 2010 that referred on an outpatient rescreening with no diagnostic follow-up reported, 112 (86.2%) received their rescreening at a facility capable of doing diagnostic evaluation.

A more significant barrier to diagnostic testing may be appropriate follow-up for children who are identified with transient conductive hearing loss and require medical management prior to additional audiologic testing. Of the children lost between rescreening and diagnostic testing, 49.4% 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: For the EI match done for 2009 births, the primary reason for children to not be enrolled (48%) was parent unresponsiveness to contact by case managers. Twenty-two percent of families declined EI services, for 17% the infant expired or moved out of state, and in 13% the family could not be contacted. The remaining 22% declined EI services. Therefore a demonstrated need for improved EI enrollment is better parent education of the benefits of EI services.

Current Implementation of NICHQ Recommended Strategies: During 2008 hospital reviews, the strategies developed from the initial NICHQ Learning Collaboratives were presented and each hospital was asked to implement one or more of the strategies. When discussed again during the 2009 hospital review, all hospitals had implemented at least one of the NICHQ recommendations with Table 3 showing the use of each strategy. Some hospitals made adaptations to the NICHQ recommendations. For example, most hospitals do not fax results to the primary care providers, but instead mail them. Some hospitals found that faxing was less likely to get the results into a child's chart since if they were received before the child had been to the office for an initial visit, the results were not placed in the provider's chart for the child.

Table 3: Hospital utilization of NICHQ strategies (of 51 hospital reviews)

NICHQ strategy	Number of hospitals implementing as described	Number of hospitals implementing with variation
Scripting the screeners message to parents	45	4
Ascertaining the name of the infant's primary care provider	41	3
Identifying a second point of contact for the family	41	0
Making rescreening or audiology appointments for the infant at hospital discharge	15	0
Telephone reminders for appointments	25	10
Fax-back of results to the primary care provider	16	32

The patient volume, sociodemographic profile, and audiology services available at each New Jersey hospital vary widely. As such, strategies that work in one facility may not work well in another. For example, some New Jersey hospitals have reported that they have tried the NICHQ strategy of making a follow-up appointment prior to hospital discharge only to have exceedingly high no-show rates. As noted previously in Table 2, 30% of 2010 births that were lost to follow-up did have at least one appointment scheduled, but missed that appointment. However, other hospitals have implemented this strategy with great success. Implementation is also varied for the non-hospital based NICHQ strategies.

Use of Fax-back forms between multiple providers: Most audiology facilities do send outpatient follow-up results to the provider, though mainly through regular mail instead of fax.

Scheduling two audiology appointments two weeks apart at hospital discharge: This was recommended during a conference call for audiologists held in 2010. In a recent survey of audiology facilities, 6% reported currently using this strategy and 40% of the facilities stated they did not think it was a practical strategy for their facility.

Streamlining the EI referral process and obtaining a consent for release of information: In 2008, the New Jersey EI program set up one toll-free phone number as the intake point for EI services, in an effort to streamline enrollment. A procedure to obtain parental consent for release of information to the EHDI program is currently in the preliminary stages of implementation.

Improving data tracking systems: The New Jersey EHDI program currently has mechanisms in place to track children from screening to early intervention utilizing existing electronic data systems. Improvements in the data aggregation are continually being made.

Assignment of a dedicated follow-up coordinator: In New Jersey, the primary responsibility for ensuring outpatient follow-up lies with the birth facility. Each hospital is required to designate a primary EHDI contact. The EHDI program concurs that the level of dedication by the hospital's EHDI coordinator is related to follow-up success. A current grant with the Mercer County Special Child Health Services (SCHS) Case Management Unit (CMU) provides for dedicated follow-up staff to pick up where hospital efforts have failed.

Methodology:

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 100% from this grant. The EHDI Program's other full time staff (EHDI Audiologist, Research Scientist, and Senior Clerk) and the Program Manager will also contribute to the grant activities. Subgrant funding for four projects will also support the goals of the grant. Funding will be provided to the Mercer County SCHS CMU, to the New Jersey EI program, to five Federally Qualified Health Centers (FQHC), and to the Statewide Parent Advocacy Network (SPAN). 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. Lost 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.

Data system: The Department of Health and Senior Services (DHSS), through funding received from the Centers for Disease Control and Prevention (CDC), has developed a data system that will enable monitoring the impact of the project and conducting quality improvement activities. EHDI administrative rules mandate that inpatient newborn hearing screening results be reported electronically to the DHSS via the EBC. The EHDI administrative rules require the Newborn Hearing Follow-up Report (SCH-2) form (Attachment 9-1) be submitted for all outpatient testing of infants and toddlers. Providers are also mandated to report children identified as lost to follow-up (i.e., unresponsive to reminder contacts, parents refuse follow-up services, child died or moved out of state, etc.) on the Lost to Hearing Follow-up Report (SCH-3) form (Attachment 9-2). These forms can be completed either on paper, or electronically using an interface developed in the New Jersey Immunization Information System (NJIIS) in 2006.

The Special Child Health Services (SCHS) Registry is a comprehensive, confidential database that provides unduplicated data on children with birth defects and special needs. Within 10 days of receipt of a SCHS registration, copies are forwarded to the appropriate county 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.

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.

Hospital discharge to outpatient rescreening: To improve the likelihood of families receiving follow-up services, the PHNC will work with hospitals in improving follow-up rates and will facilitate strategies developed in the NICHQ Learning Collaborative. New Jersey's EHDI law and rules make each hospital, rather than the New Jersey EHDI program, responsible for ensuring outpatient follow-up. A benefit of having the responsibility for follow-up fall to the hospital is in sustainability. Since hospital efforts to ensure follow-up are mandated in administrative rules, they will continue regardless of availability of State EHDI staff. The PHCN will work to help hospitals implement sustainable efforts that will ensure outpatient follow-up. The PHCN has conducted annual hospital reviews since 2003 to review hospital policies, procedures, and performance. Hospitals are also given the opportunity to learn from each other and share best practices through mandatory annual meetings held in three regional locations.

The EHDI program conducts case reviews during annual conference calls for children who were reported as referring on inpatient screening but have no outpatient follow-up reported. One result of prior reviews is that hospitals have found that some inpatient refer results were EBC 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.

Prior case reviews conducted by the EHDI staff identified financial barriers to receiving follow-up. To address this need, the New Jersey EHDI program provided funding from the current HRSA grant to five FQHCs in New Jersey to purchase screening equipment and train staff. The FQHCs agreed to provide rescreening services at no cost to any family referred to their facility. The proposed budget includes funding to these FQHCs to allow for continued equipment maintenance and supply purchases to allow this initiative to continue. See Attachment 6-1 for letters of support.

The EHDI Research Scientist will continue to provide each facility quarterly EHDI reports (Attachment 1-2). The reports include a listing of children who have a failed or missed screening with no follow-up documented. Semi-annually, additional detail reports are sent to each facility. Reports indicating completed follow-up, possible EBC errors, and compliance with JCIH recommendations are included as well as summary statistics for hospital-specific and overall State screening rates, refer rates, and follow-up rates. Facilities are encouraged to use these reports to ensure children receive follow-up and for internal quality assurance.

Using current HRSA funding, the EHDI program made a New Jersey version of the Hands & Voices *Loss & Found* video during 2011. This video was designed for parents whose children did not pass inpatient screening to reinforce the need for prompt follow-up and to allay parent fears about the refer result on the initial screening. During the new funding cycle the PHCN will monitor hospital distribution of this DVD to parents of children that refer on inpatient screening.

After discharge, hospitals are required to make 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 Mercer CMU staff for additional efforts to contact the parents and connect the family to follow-up services. For the 835 cases of 2010 births referred to the CMU for this additional outreach, 74 (8.9%) were EBC data entry errors (the parent reported the child passed screening before discharge) and 452 (54.3%) had additional follow-up testing completed as a result of the additional reminder. The remainder were unresponsive to contact efforts or were unable to be contacted. This outreach will be continued during the proposed funding period. See Attachment 6-2 for a letter of support.

Another outcome of the case reviews and CMU outreach has been finding families who received follow-up, 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 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 6-3 for letter of support.

The EHDI audiologist will 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 audiology facilities each year throughout the funding period to provide technical assistance, training, and guidance. The EHDI Program has created an email distribution list of pediatric audiologists in New Jersey, which will be utilized for important EHDI announcements.

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 will ensure that the information in the Pediatric Hearing Health Care Directory is updated annually and is available on the EHDI web site.

Outpatient rescreening to audiologic diagnosis: The EHDI program will continue to utilize the Mercer CMU staff to conduct outreach to families and physicians for children who have been referred on outpatient rescreening and no diagnostic exam has been received within six weeks. Outreach specifically to this group of children with incomplete follow-up began in October 2009. For 2010 births, 260 cases meeting this criterion were referred to the CMU. Of these, 52.3% 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.

During this grant cycle, the EHDI program will add a new method for notifying physicians caring for children needing audiologic diagnosis. The EHDI program will utilize wording suggested at the 2011 National EHDI meeting, identifying an outpatient rescreen refer as a “developmental emergency.” A database query will be developed by the Research Scientist so that a standard letter can be generated by the PCHN and sent to the primary care provider, indicating the importance of assuring additional follow-up testing. Since the primary care provider is not always noted on the follow-up report form, additional work will be required by the Senior Clerk. She will check other data sources to identify the primary provider, such as the provider information captured in the EBC, or will contact the examining audiologist.

As another effort to ensure diagnostic testing after outpatient rescreening, the Research Scientist will create new reports that will be distributed 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. The goal of this effort is to assist facilities in identifying children that need to be recalled to the facility for further testing. The EHDI Audiologist will work with facilities identified with above average rates of loss to follow-up between outpatient follow-up and diagnosis to implement strategies to improve completion of follow-up testing.

Diagnosis to early intervention: Adoption of the NICHQ recommendation of obtaining consent for release of information at first contact with Early Intervention (EI) is currently in process in New Jersey. The current Child Find match of SCHS Registry and EI data enables the EHDI program to obtain information on EI enrollment of children with hearing loss. This procedure will be maintained during the grant period. However, obtaining parental consent will allow for more timely access to the information, and will allow the EHDI program to more quickly investigate cases where Early Intervention was not initiated.

In addition, the EHDI program will reach out to programs that may be providing services outside of the Part C program. Since participation in the State Part C program is voluntary and since some services are subject to a cost share which requires the family to share income data, some families may elect to find services privately. Thus, implementing consent forms to allow programs working with hearing impaired children to share data with the EHDI program will improve information about the services received.

During the current HRSA funding period, the New Jersey EHDI program worked with the Early Intervention program to create a new consultant position that for a specialist in hearing loss. This position is expected to be filled and begin providing services in early 2012. A goal for this consultant is to establish contact with the families soon after diagnosis to guide them into EI services. The consultant will also be a participant at the initial family meeting via a telehealth/web conferencing approach to provide guidance on selecting a communication approach and EI services that are appropriate for that family. This project will continue through all three years of the proposed funding period. See Attachment 6-4 for letter of support.

The EHDI Audiologist will 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 can encourage the family to make contact with EI and/or respond to calls from case managers, to facilitate their timely EI enrollment.

Learning Collaborative: New Jersey will participate in the next NICHQ Learning Collaborative to decrease loss to follow-up at all the points previously noted where children may be lost to follow-up. In order to engage community stakeholders in the process, the EHDI program will provide funding to the Statewide Parent Advocacy Network of New Jersey (SPAN). The EHDI program will benefit from SPAN’s relationship with the parent community, aiding our ability to identify parent members of the Learning Collaborative Team. In addition, SPAN has current experience with Learning Collaboratives, having implemented a Medical Home initiative using this model. See Attachment 6-5 for letter of support.

SPAN is New Jersey's federally-designated Family to Family Health Information Center and Family Voices State Affiliate Organization, and houses three HRSA-funded State Implementation Grants (SIG). Through these initiatives, SPAN staff and key members of the New Jersey core team participated in an intensive NICHQ Jumpstart Quality Improvement Learning Collaborative. As part of these projects, SPAN is co-facilitating a series of Medical Home Learning Collaboratives for pediatric and primary care practices, including FQHCs. To date, several Learning Collaboratives have been held, others are scheduled to occur this fall and winter. Each of the Learning Collaboratives has received outstanding evaluations from the participating practice teams, including parent partners. The evaluation of the first set of Learning Collaboratives has demonstrated a significant improvement in "medical homeness" as measured by the Center for Medical Home Improvement Medical Home Index and family surveys. Since a key component of reducing loss to follow-up is ensuring physicians make necessary referrals for follow-up, and coordinating care services from multiple providers for children diagnosed with hearing loss, the EHDI program is hopeful that some common ground will be identified between the EHDI and Medical Home Learning Collaboratives, to allow for synergy of activities.

SPAN will be responsible for identifying two non-State staff, including at least one parent, to participate in the regional Learning Collaborative sessions and arranging for their travel to the out-of-state meetings. They will handle logistics for local team meetings and will give guidance to the EHDI program based on their Medical Home Learning Collaborative experience.

The goal for the Learning Collaboratives will be to identify at least two objectives for each of the areas of loss to follow-up (discharge to rescreening, rescreening to audiologic testing, and diagnosis to early intervention enrollment), and implement rapid cycles of change for each of those objectives. The Learning Collaborative team, SPAN, and EHDI staff will be responsible for the developing the objectives and identifying initiatives to test. The PHCN and the Research Scientist will be responsible for data analysis to determine the effectiveness of the interventions.

Work Plan

The proposed goals, objectives, activities, timelines, responsible staff, and evaluation measures are given in Table 4. Personnel abbreviations are: PHCN= Public Health Consultant – Nursing, EA=EHDI Audiologist, RS=Research Scientist, SC=Senior Clerk, AAP-CC=American Academy of Pediatrics' EHDI Chapter Champion, EIC = Early Intervention Consultant, SPAN=Statewide Parent Advocacy Network, and LC Team = Learning Collaborative Team

Table 4: Goals, Objectives, Activities, Timelines and Evaluation

Goal 1: By March 31, 2015, reduce the rate of infants lost to follow-up between hospital discharge and outpatient screening to no more than 8%.			
Measurement: Percent of babies who referred on inpatient screening that had follow-up documented. Goal: 92% by 3/31/15, baseline: 80.9% for 2010 births. Percent of babies who referred on inpatient screening that have *timely* follow-up documented. Goal: 87% by 3/31/15, baseline: 64.7% for 2010 births.			
Objective 1.1: Hospital technical assistance will create annual improvements on rates of infants receiving timely follow-up after referring on inpatient screening.			
Activities	*Timeframe*	*Person(s) Responsible*	*Evaluation/Measurement:*
Conduct annual regional meetings or conference calls for hospital EHDI contacts to promote best practices.	September 2012, 2013 and 2014	Primarily PHCN, with assistance by EA, RS	Number of regional meetings held. Number of attendees.
Throughout the funding cycle, distribute hospital-specific quarterly reports which will include refer rates, follow-up rates, and unduplicated individual data on all children not passing initial screening.	February, May, August and November of each year	RS	Document distribution date and number of recipients.
Conduct annual hospital reviews to evaluate statistics and to verify accuracy and implications of the quarterly report data and conduct case reviews for all children with unknown follow-up status.	September through December of each year	Primarily PHCN, with assistance by EA, RS	Number of reviews conducted. Number of other technical assistance contacts. Number of cases reviewed. Summary outcome of each case review.

Objective 1.2: Decreasing family barriers to rescreening will create annual improvements on rates of infants receiving timely follow-up after referring on inpatient screening.

Activities	*Timeframe*	*Person(s) Responsible*	*Evaluation/Measurement:*
Hospitals will distribute *Loss & Found* DVD to parents of infants who do not pass inpatient screening to reduce parental uncertainty and anxiety as a barrier to rescreening.	4/1/12-3/31/15	PHCN, hospital staff	Number of DVDs distributed to hospitals.
FQHCs will offer free rescreening to reduce financial barriers to rescreening.	4/1/12-3/31/15	FQHCs	Number of rescreening exams conducted at each FQHC.
Pediatric Hearing Health Care Directory will be updated at least annually to reduce inability to locate facilities as a barrier to rescreening.	July 2012, July 2013, July 2014	RS, SC	Document outreach contacts to currently listed facilities. Document number of listing updates completed.
Conduct reminder phone calls to parents of children that refer on inpatient rescreening and have not had additional testing completed within 6 weeks.	4/1/12-3/31/15, new cases provided weekly	Mercer CMU	Number of cases referred to CMU. Number of contact attempts made. Final follow-up status for referred cases.

Objective 1.3: Improved outpatient reporting of rescreening and diagnostic exams will create annual improvements on documentation of follow-up after referring on inpatient screening.

Activities	*Timeframe*	*Person(s) Responsible*	*Evaluation/Measurement:*
Conduct site visits, phone calls, or group meetings to at least 30 audiologists annually targeting at improving reporting.	4/1/12-3/31/15	EA	Number of educational activities conducted. Number of audiologists educated.
Conduct site visits, phone calls, or group meetings to at least 30 physicians annually targeting at improving reporting.	4/1/12-3/31/15	PHCN, AAP-CC	Number of educational activities conducted. Number of physicians educated.

Goal 2: By March 31, 2015, reduce the rate of infants lost to follow-up between outpatient rescreening and diagnostic testing to no more than 10%.

Measurement: Percent of babies who referred on outpatient rescreening who have diagnostic audiology evaluation completed. Goal: 90% by 3/31/15, baseline: 33.8% for 2010 births. Percent of babies who referred on outpatient screening who have *timely* diagnostic audiology evaluation completed. Goal: 80% by 3/31/12, baseline: 21.7% for 2010 births.

<table>
<tr><td colspan="4">Objective 2.1: Outreach to parents after a refer result on outpatient rescreening will create annual improvements on rates of infants receiving timely follow-up after referring on outpatient rescreening.</td></tr>
<tr><td>Activities</td><td>Timeframe</td><td>Person(s) Responsible</td><td>Evaluation/Measurement:</td></tr>
<tr><td>Conduct reminder phone calls to parents of children that refer on outpatient rescreening and have not had additional testing completed within 6 weeks.</td><td>4/1/12-3/31/15, new cases provided weekly</td><td>Mercer CMU</td><td>Number of cases referred to CMU.
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<tr><td colspan="4">Objective 2.2: Outreach to physicians after a refer result on outpatient rescreening will create annual improvements on rates of infants receiving timely follow-up after referring on outpatient rescreening.</td></tr>
<tr><td>Activities</td><td>Timeframe</td><td>Person(s) Responsible</td><td>Evaluation/Measurement:</td></tr>
<tr><td>Develop and implement a process for sending letters to physicians of children who refer on outpatient rescreen.</td><td>Develop programming and form letter by 12/31/12
Weekly letter generation from 1/1/13-3/31/15</td><td>RS
PHCN, SC</td><td>Document number of letters mailed each week.
Document final follow-up status for children who initially referred on outpatient rescreening.</td></tr>
</table>

<table>
<tr><td colspan="4">Objective 2.3: Outreach to audiologists will create annual improvements on rates of infants receiving timely follow-up after referring on outpatient rescreening.</td></tr>
<tr><td>Activities</td><td>Timeframe</td><td>Person(s) Responsible</td><td>Evaluation/Measurement:</td></tr>
<tr><td>Create audiology facility-specific reports to aid facilities in identifying children that need to return for further follow-up.</td><td>Design and program reports by 6/30/13
Quarterly report generation from 71/13-3/31/15</td><td>RS
RS, SC</td><td>Document distribution date and number of recipients.
Document trends in facility-specific follow-up rates.</td></tr>
</table>

Goal 3: By March 31, 2015, reduce the rate of infants lost to follow-up between hearing loss diagnosis and early intervention enrollment to no more than 10%.
Measurement: Percent of babies with hearing loss who are enrolled in early intervention Goal: 90% by 3/31/15, baseline: 65.3% for 2009 births (71.3% excluding families that declined enrollment, or infants that died or moved out of state) Percent of babies with hearing loss who are enrolled in early intervention by 6 months of age Goal: 85% by 3/31/15, baseline: 36.7% for 2009 births. (40.2% excluding families that declined enrollment, or infants that died or moved out of state)
Objective 3.1: Rate of early intervention enrollment after a hearing loss diagnosis will increase annually during the grant cycle.

Activities	*Timeframe*	*Person(s) Responsible*	*Evaluation/Measurement:*
Perform annual reconciliation of EHDI and EI data to ensure all children with hearing loss are accounted for in tracking system.	January 2013, January 2014, January 2015	RS, PHCN	Percent of initial system matches. Documentation of resolution of non-matches.
EI hearing loss consultant will make contact with newly diagnosed families to encourage EI enrollment.	4/1/12-3/31/15	EIC	Documentation of number of families contacted. Documentation of reasons for non-enrollment.
Collaborate with Part C and non-Part C Early Intervention providers to obtain parental consent on first contact to release data to the EHDI program.	4/1/12-3/31/15	PHCN	Percent of EI families signing consent.
Conduct education to audiologists to encourage families of newly diagnosed children to immediately contact EI for services.	4/1/12-3/31/15	EA	Documentation of educational efforts. Number of audiologists educated.

Goal 4: By March 31, 2015, implement at least six effective interventions to decrease loss to follow-up via participation in the Learning Collaborative model.			
Measurement: Number of Learning Collaborative interventions that demonstrate measureable improvement in the targeted outcome. Goal: Six			
Objective 4.1: By March 31, 2015, achieve success on at least two Learning Collaborative objectives targeting outpatient follow-up after hospital discharge.			
Objective 4.2: By March 31, 2015, achieve success on at least two Learning Collaborative objectives targeting diagnostic evaluation after rescreening refer.			
Objective 4.3: By March 31, 2015, achieve success on at least two Learning Collaborative objectives targeting early intervention enrollment after hearing loss diagnosis.			
Activities	*Timeframe*	*Person(s) Responsible*	*Evaluation/Measurement:*
Recruit Learning Collaborative team members	4/1/12-11/1/12	PHCN, SPAN	Documentation of outreach efforts. Documentation of final LC Team membership.
Participate in National NICHQ Learning Collaborative sessions	11/2012, 4/2013, 9/2013	PHCN, LC Team	Documentation of attendance.
Identify and implement small tests of change	10/1/12-3/31/15	PHCN, SPAN, RS, LC Team	Document LC Team meeting minutes. Document interventions attempted.

Evaluate effectiveness of small tests of change	1/1/13-3/31/15	PHCN, SPAN, RS, LC Team	Document change in follow-up rates for targeted areas. Document intermediate outcomes determined by LC Team.

Ongoing review of the work plan by stakeholders will be a function of the New Jersey Hearing Evaluation Council. New Jersey's hearing screening legislation mandates the existence of the Council 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 fill the "concerned citizen" and the hard of hearing position. The Council has held meetings three to four times each year since December 2005.

Resolution of Challenges

Medical Home Identification: The important role of the primary care provider in ensuring follow-up has been noted, and increased contact with providers, such as sending letters to providers of children that refer on outpatient rescreening is planned for the proposed grant. The ability to identify the correct and current provider may well be a challenge. However, as previously noted, the EHDI program is hopeful that the requirement for physicians to document immunization data in the NJIIS beginning at the end of 2011 will improve the program's ability to identify the provider currently caring for the child.

FQHC Rescreening: To date the FQHCs with rescreening equipment have conducted fewer exams than expected. The EHDI program has determined that the biggest barrier is identifying the infants that might need this referral before hospital discharge so that a rescreening can be scheduled in the first month of life. When follow-up contacts reveal that a child hasn't received follow-up due to lack of insurance coverage, the child is often too old to be rescreened in the FHQC setting. During Fall 2011 regional meetings, the EHDI program asked hospital staff to identify children that will benefit from the FQHC service and make the referral before discharge.

Parent motivation: All families of children lost to hearing follow-up in New Jersey receive at least one outreach attempt and often several, yet have not acted on the recommendation to seek further evaluation. The EHDI program will continue to seek ways to instill the importance of follow-up in families, including emphasis on scripting the message given to parents after inpatient screening and providing the *Loss & Found* DVD.

Evaluation and Technical Support Capacity

All EHDI project staff have served in their current roles for at least 7 years (see job descriptions in Attachment 2 and biographical sketches in Attachment 3). The Program Manager has been with the State since 1990 and directly responsible for the EHDI program since 1999. The PHCN joined the EHDI program in 2004, the Senior Clerk and Audiologist in 2003, and the Research Scientist in 2002. This long experience with the program, and in working with our hospital and audiology contacts, 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, RN, MSN is the Public Health Consultant - Nursing for the EHDI Program and has over 20 years of experience with the New Jersey Department of Health and Senior Services (DHSS). In her current EHDI position and in her previous work with the SCHS Registry program she has conducted annual evaluations of hospital compliance with State rules. In a prior position within the DHSS, Ms. Biando managed the State's HealthyStart grants. This required extensive evaluation of multiple grantees on the effectiveness of their initiatives to reduce fetal and infant mortality.

Nancy Schneider, MS, CCC-A, FAAA is the Research Scientist 2/Audiologist for the EHDI Program. The majority of her pediatric clinical audiology experience was at a university teaching hospital, which included responsibility for supervision of clinical fellows and graduate interns. 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 currently serves as chair of the New Jersey's 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, RNC, MPH is the Research Scientist 1 for the EHDI Program. In her prior position as Director of Quality Assurance for a non-profit maternal-child health agency, she did data analysis using Electronic Birth Certificate data from hospitals in the region. She also was responsible for development of professional education. She conducted regular program evaluation meeting with several grant coordinators. This involved regular review of progress toward grant goals and objectives, as well as strategizing on necessary adjustments to activities when goals were not being met. The grants included two Healthy Mothers/Health Babies programs; a Black infant mortality reduction program; a grant to increase enrollment in FamilyCare, New Jersey's State Children's Health Insurance Program; and a fetal-infant mortality review grant. In addition, Ms. Aveni has completed a Juran Institute course in "Facilitating and Leading Quality Improvement Teams."

Leslie Beres-Sochka, MS, CPM, is the Program Manager and has primary responsibility for the Early Identification and Monitoring Program, including the EHDI Program and the SCHS

Registry. She has over 20 years experience in research, statistical analysis, and database design/management, grants management, and in the administration of screening and surveillance programs. She is the Principal Investigator on the CDC EHDI and CDC Birth Defects Surveillance cooperative agreements.

The New Jersey EHDI program evaluates progress toward screening and diagnostic follow-up semi-annually. Hospital-specific reports are distributed and Statewide data is also calculated. The EHDI program reviews performance internally and also with the Hearing Evaluation Council to identify areas of need. Additionally, the Research Scientist runs hospital-specific screening and refer rates weekly when uploading data from Vital Statistics. Any outliers will result in a call to the hospital to determine if the hospital is experiencing equipment problems. EI enrollment goals are currently assessed annually through the previously mentioned data match. When the EI hearing loss consultant position is filled in early 2012, there will be a monthly assessment of EI status for all documented cases of hearing loss, improving the timeliness of the assessment of this evaluation measurement.

To nationally disseminate the results of their achievements, EHDI staff have given or co-authored nine national EHDI meeting presentations or posters since 2002. Most recently, the EHDI team co-authored a poster presentation “Children with Early Hearing Loss and Existing Comorbid Health Conditions in New Jersey: State Data and the Experience of Families” at the 2011 EHDI Conference. In 2009, the Research Scientist presented “Assessing and Encouraging Compliance with 2007 JCIH Recommendations.”

Organizational Information

Organizational Structure: New Jersey has 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 Department of Health and Senior Services (DHSS) (see organizational chart, Attachment 9-3). The EHDI Program is administered through the Division of Family Health Services (FHS), headquartered in Trenton, New Jersey, which has sufficient space, equipment, and facilities to house this project. The mission of Family Health Services is to work to promote and protect the health of mothers, children, adolescents, and at-risk populations, and to reduce disparities in health outcomes by ensuring access to quality comprehensive care.

FHS consists of four service units: Maternal and Child Health Services; Women, Infants, and Children (WIC) Services; Chronic Disease Prevention and Control Services; and Special Child Health and Early Intervention Services (SCHEIS). FHS also has three offices: Office of Nutrition and Fitness, Office of Primary Care/Rural Health, and Office of Procedural Safeguards. These units work to improve the health, safety, and well being of families and communities in New Jersey and support the goals of the MCH Block Grant. SCHEIS, the Title V program for children with special health care needs, is comprised of four programs,: Early Identification and Monitoring (EIM), Newborn Biochemical Screening and Genetic Services (NS&GS), Family Centered Care Services (FCC), and the Early Intervention System (EIS).

EIM is responsible for maintaining the EHDI Program, the Autism Registry, and the SCHS Registry. NS&GS is responsible for tracking all newborns with abnormal bloodspot screens and ensuring that these children are rescreened, and in treatment if diagnosed with a disorder. FCC is responsible for 21 county-based case management units and the HIV Family Centered Care Network. In July 1993, the EIS program was designated the lead agency for Part C of the Individuals with Disabilities Education Act (IDEA) when these services were transferred to

DHSS from the Department of Education. This organizational structure facilitates the cooperation and collaboration necessary for a successful EHDI.

Relationships with other Divisions of the DHSS include those with the NJIIS program in the Division of Epidemiology, Environmental, and Occupational Health. A strong relationship in another DHSS division is with the Bureau of Vital Statistics and Registration, in the Office of the Commissioner. This unit ensures that EBC data is provided to the EHDI Program and has partnered with EHDI staff to include new hearing fields in the EBC system.

Collaboration with the New Jersey Division of the Deaf and Hard of Hearing (DDHH) in the Department of Human Services has included membership on the Deaf and Hard of Hearing Advisory Council, collaborating on a parent education brochure, and working together on the biennial Family Learning Day Conference for families having children with hearing impairment. The EHDI Program has also established successful working relationships with staff from the Department of Education and assisted that department with development of a parent information packet for children with hearing loss.

Law and Rules: In 1977, New Jersey passed a law and implemented rules requiring hospitals to assess newborns for the presence of risk indicators for hearing loss and notify the DHSS. Public Law 2001, Chapter 373, passed in January 2002, requires universal electrophysiologic newborn hearing screening to be performed by 30 days of age, requires hospitals to have guidelines for ensuring the provision of follow-up services, and mandates reporting of children with hearing loss. The law requires screening all newborns, allowing for parental refusal only in if it conflicts with “the parents' bona fide religious tenets or practices.” The law also requires “a central registry of newborns identified as having or being at risk of developing a hearing loss” and the establishment of the Hearing Evaluation Council.

The administrative rules were readopted with revisions on July 5, 2011. The rules detail the roles of hospitals, audiologists, and pediatricians, and also very precisely outline the elements required for each hospital's EHDI procedures. The rules establish the most current JCIH Position Statement as the standard for selection of screening method and determining risk indicators for progressive/late-onset hearing loss and the appropriate monitoring intervals for children with these conditions. The rules require the reporting of all outpatient audiologic follow-up and also implement mandatory reporting when children are considered to be lost to follow-up. Follow-up of outpatient rescreening and diagnostic testing is required of all providers, including pediatricians conducting rescreening in their office. The requirement to report children with hearing loss, up through age 21, to the SCHS Registry is also included in the EHDI rules.