Background and Need

Significant hearing loss is one of the most common major abnormalities present at birth and, if undetected, will impede speech, language, and cognitive development. These delays can be minimized or avoided through early detection and intervention. The New Jersey Early Hearing Detection and Intervention (EHDI) program supports the national goals of screening by one month of age, diagnosis by three months of age, and early intervention by six months of age. Since the implementation of New Jersey's legislative mandate for universal newborn hearing screening in January 2002, considerable improvement has been made in meeting these goals. Screening rates for babies discharged from New Jersey hospitals have increased from 30.3% in 1998 to 99.3% in 2007. While a screening rate in excess of 99% is very successful, areas for improvement include decreasing the incidence of incomplete or missing data and collaborating with hospitals to prevent missed screenings.

Substantial improvements have also been made in follow-up rates, though this area remains a challenge. For babies born in 2002 who referred on their inpatient screening, 44.5% had follow-up testing reported to the EHDI program, and for 2006, the rate improved to 66.8%. Follow-up rates are lower for children not screened prior to discharge, with only 43.6% of these children returning for outpatient follow-up in 2006. Discussions with hospitals, audiologists, pediatricians, and parents have identified several barriers, including providers not submitting follow-up results; families receiving out of state follow-up; families declining follow-up evaluation due to perceived lack of importance, financial concerns, or other barriers; and families who move or are otherwise lost to follow-up.

Since the implementation of universal newborn hearing screening, more children have been registered with a hearing loss by three months of age, from 31 children born in 2002 to 65 for 2006 births. Yet the current documented rate of hearing loss in New Jersey is around 1.5

per 1000 births, below the nationally reported expected incidence of 3 per 1000. The EHDI program believes gaps exist in diagnosis and reporting of hearing loss, which lead to underestimation of actual rates.

Timely Early Intervention (EI) enrollment has improved over the period of universal newborn hearing screening, but is below program goals. For children born in 2004 (the first year with complete EI data available to the EHDI program), 67.6% of those with known hearing loss were enrolled in EI, with 29.7% enrolled by six months of age. For children born in 2006, the rate improved to 68.8% enrolled, and 47.7% enrolled by six months of age.

Continued Centers for Disease Control and Prevention (CDC) cooperative agreement funding is essential to the enhancement of the EHDI tracking system, to ensure children with hearing loss are screened, diagnosed, and offered EI services in a timely manner. Continued funding will enable the New Jersey EHDI program to build upon current efforts and to improve tracking through EI.

State Legislation: 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 Department of Health and Senior Services (DHSS). Public Law 2001, Chapter 373 (Appendix A), which was 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 also requires “a central registry of newborns identified as having or being at risk of developing a hearing loss.” The most recent update to the administrative rules, with a focus on mechanisms to improve follow-up, were adopted on December 19, 2005 (Appendix B).

Data Systems: Using funding from the current CDC EHDI cooperative agreement, New Jersey has established a robust database to track universal newborn hearing screening and the success in accomplishing program objectives. The current EHDI database, internally developed using Microsoft Access, was established in May 2002 and has since been continuously updated and improved. It includes data imported from a variety of sources to capture inpatient screening, diagnostic audiologic evaluations, and early intervention data. Appendix C diagrams the EHDI system data flow.

Since 1997, all New Jersey birthing facilities have used a DOS-based Electronic Birth Certificate (EBC) system to transmit newborn data via modem to the Bureau of Vital Statistics and Registration (BVSR). Weekly data files containing all EBC fields required by the EHDI program are created by the BVSR, are downloaded from secure servers, then merged into the EHDI database, with procedures to avoid duplicates and capture any updated records. Using EBC data has many advantages including receipt of standardized data, capture of over 99% of occurrent births, and the ability to obtain extensive demographic and clinical information.

Outpatient audiologic testing is reported on the Newborn Hearing Follow-up Report (SCH-2) form (Appendix D) which can be submitted as a paper form, or electronically via an EHDI interface that was incorporated in the New Jersey Immunization Information System (NJIIS). The NJIIS is populated with EBC data. A 2004 law requires that all children be enrolled in the NJIIS unless the parent refuses participation. In 2006, an EHDI module was added to the NJIIS to allow providers to view hearing evaluation data and to electronically submit EHDI outpatient follow-up report forms.

The NJIIS is a secure, authenticated, Web system with role-based access to the various modules. Primary care providers can view hearing screening data in addition to viewing and editing immunization data. Audiologists can access evaluation results and report outpatient testing results, but cannot access the immunization section of the system. Over 100 audiologists and others who conduct outpatient screening or track follow-up have been trained by EHDI staff to use the NJIIS-EHDI module. At present, approximately 75% of outpatient hearing follow-up reports are submitted to the EHDI program through the NJIIS. When providers elect to submit paper follow-up forms, these are entered into the NJIIS by the EHDI program clerk. Extracts from the NJIIS system are routinely created and imported into the Access database for tracking and report generation.

The Special Child Health Services (SCHS) Registry is a comprehensive, confidential database that provides unduplicated data on children with birth defects and special needs. New Jersey legislation mandates reporting of all children diagnosed with birth defects through five years of age. SCHS registration of children through age 21 with hearing loss is required by the EHDI rules. Within 10 days of receipt of a SCHS registration, copies are forwarded to the appropriate county Case Management Unit (CMU), which is the single point of entry for Early Intervention (EI) services in New Jersey.

Documentation of a diagnosed hearing loss for the EHDI tracking system is achieved through two sources, SCH-2 forms and SCHS Registration (SCH-0) forms. Since the SCHS Registry results in a link to services, the Public Health Consultant - Nursing routinely does a manual cross-check on all SCH-0 and SCH-2 forms to ensure all required documentation is complete. Additionally, a file generated quarterly from the SCHS Registry database, which includes both children with hearing loss and also those registered with diagnoses that are risk indicators for progressive/late-onset hearing loss, is matched to the EHDI database to ensure all cases of hearing loss are identified.

During 2004, the EI program implemented a comprehensive Statewide electronic data system, known as System Point of Entry (SPOE). It includes demographics, family data, referral source, enrollment information, detail on the child’s conditions, and extensive detail on the EI services being received. Data from the SPOE system is utilized to track EI enrollment for children with hearing loss.

Reporting Protocols: Reporting via the EBC of inpatient hearing screening results and risk indicators for progressive/late-onset hearing loss within 5 days of discharge is mandated by EHDI administrative rules. These rules also require the SCH-2 form be submitted for all outpatient testing of infants and toddlers, including initial outpatient screening on babies not previously screened, repeat screening, diagnostic testing, and routine audiologic evaluation for children with risk factors for progressive/late-onset hearing loss. 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.), either on paper or via the NJIIS on the Lost to Hearing Follow-up Report (SCH-3)(Appendix E). Since diagnosis of hearing loss is captured on both the SCH-2 form and the SCHS Registry, some cases are identified that might otherwise be lost to documentation. New Jersey cannot require out-of-state audiologists to comply with the SCH-2 reporting requirement. However, if the child sees a New Jersey pediatrician, that physician is required to report the hearing loss via the SCHS Registry.

Reporting of EI status is part of a broader collaboration and part of 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 is used to track performance toward EI enrollment goals for children with hearing loss.

Collaborative Relationships: New Jersey has a strong infrastructure to support the EHDI program, 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 DHSS - see organizational charts, Appendix F. The EHDI Program is located in the same service unit as the SCHS Registry, Family Centered Care Services (with responsibility for the county CMUs), and the Part C EI program. This organizational structure has facilitated data sharing and collaborative efforts.

Other collaborative relationships within the State, described later in further detail, include work with the NJIIS in the Division of Epidemiology, Environmental, and Occupational Health; the EBC program in the Bureau of Vital Statistics and Registration; the Division of the Deaf and Hard of Hearing in the Department of Human Services; and with the Office of Special Education in the Department of Education. Collaborative relationships outside of State agencies include relationships with birthing hospitals, audiology facilities, the New Jersey Chapter of the American Academy of Pediatrics, the Parent-to-Parent support program of the Statewide Parent Advocacy Network, and the Hearing Evaluation Council. See letters of support in Appendix G.

Work Plan

New Jersey has taken significant steps towards establishing a comprehensive EHDI tracking and surveillance system. The purpose of this project is to expand and enhance the existing EHDI data system to improve the quality and timeliness of data, to establish linkages with new data systems, and to improve tracking of screening, follow-up, and EI enrollment. See Appendix H for a detailed table indicating the goals and objectives, timeline, responsible staff, program activities and evaluation methods. To meet the overall EHDI goals of screening all infants by one month of age, completing diagnostic testing on all children who do not pass screening by three months of age, and ensuring EI enrollment for all children with hearing loss by six months of age, these goals, objectives, and activities are proposed:

<u>Goal 1</u>: Enhance a sustainable New Jersey Statewide EHDI surveillance and tracking system to accurately identify, match, and collect unduplicated individual identifiable data.

Obj. 1.1: In collaboration with the Bureau of Vital Statistics and Registration, by June 30, 2009 ensure that the request for proposals and any accepted bids for a new Web-based Electronic Birth Registration System (EBRS) include all necessary EHDI tracking system elements.

Obj. 1.2: In collaboration with the Bureau of Vital Statistics and Registration, by June 30, 2011 ensure that the new Web-based EBRS contains data on inpatient hearing screening and risk indicators for progressive/late onset hearing loss for all occurrent births, and ensure data are available to the EHDI program.

Obj. 1.3: Prior to implementation of the Web-based EBRS, conduct an annual data match each November with the prior year's New Jersey birth file to ensure that hearing screening statistics are documented on all occurrent births, including home births.

Obj. 1.4: Conduct annual hospital site visits and/or technical assistance conferences to review statistics and verify accuracy and implications of quarterly report data.

Obj. 1.5: Annually throughout the funding cycle, on all hospital-based occurrent births, achieve a 0% rate of cases of "unknown" inpatient hearing screening, and document reasons for 100% of missed infants utilizing individual case review.

Obj. 1.6: Beginning July 1, 2009, implement case review for all children with undocumented follow-up status and pediatrician contact for all children with incomplete follow-up.

Obj. 1.7: Via site visits, presentations at meetings, and/or direct mailing, conduct educational outreach regarding reporting requirements to ensure appropriate referrals for diagnostic testing and complete capture of outpatient testing results, with at least 50 pediatricians, 50 audiologists, and 10 pediatric otolaryngologists contacted each year of the funding cycle.

Methods for Goal 1: A significant focus of the upcoming three year period will be a successful integration of inpatient screening and risk indicator information required by the EHDI program into a new Web-based Electronic Birth Registry System (EBRS) currently being planned. New Jersey's current EBC is functionally unchanged from the system initially implemented in 1995, relying on batched modem transmission of data and a non-Windows environment. The BVSR is currently developing a Request for Proposals (RFP) to solicit bids to plan, develop and implement the conversion of the current DOS-based EBC to an online, Web-based EBRS which would be compliant with the 2003 U.S. Standard Certificate of Live Birth as well as with National Association of Public Health Statistics and Information System (NAPHSIS) guidelines. In addition to improving the timeliness, quality, and security of New Jersey's birth data, the goal of the BVSR is that adoption of a web-based EBRS would facilitate real-time linkages to other data sets, thus laying the groundwork for the development of an electronic child health record.

Several challenges for the EHDI program result from the use of the current EBC system. The weekly update of files given to the EHDI program delays data availability. Planned home births are not included in the current EBC, though they represent only about 400 (0.3%) of New Jersey births annually. Also, since there is no EBC linkage between hospitals, transferred babies have a separate record created at each hospital. The Research Scientist routinely performs electronic and manual matching to compare EBC files a complete state births file maintained by BVSR in order to identify and reconcile transfers, home births, and duplicate records. A Web-based system will improve timeliness of data, since records will be started prenatally by the obstetrician, and hearing results will be available to the EHDI program as soon as they are entered. A Web-based system will also prevent duplicate records on transferred babies since hospitals will be able to access records started at another facility.

The expectation is that the RFP will be completed and bids will be solicited during the next 12 months, with a contract to be awarded in 2009. After the award of a contract, the implementation of a new system is expected to take 18 to 24 months to complete. The EHDI staff has committed to reviewing the RFP and providing feedback on submitted bids with respect to the new system meeting the EHDI program needs.

The EHDI program will continue annual hospital site visits and other contacts to review statistics, discuss best practices, and provide technical assistance. These are conducted primarily by the Public Health Consultant - Nursing and by the Information Technology Specialist with some attended by the Research Scientist or EHDI Audiologist. The EHDI program will evaluate the current visit strategies and consider the use of telephone conference call "visits" and regional "best practice" meetings as additional or alternative strategies for providing technical assistance to hospitals in the most efficient and effective format.

A new area of focus for the quality assurance for the funding cycle will be a "zero tolerance" policy for unknown inpatient hearing screening results, and a case-by-case review of missed screenings. For 2007, 581 babies (0.55% of discharges) had no screening documented before hospital discharge. These babies fall into three categories: the parent refused screening for 22 (3.8%), hearing screening status was "unknown" for 122 (21%), and hearing screening was not done before discharge for 437 (75.2%). Refusal rates are unlikely to change since New Jersey's law only allows for a religious exemption. Unknown screening status may reflect untested children, but are more likely due to incomplete EBC data. Currently, the EHDI program produces quarterly reports (Appendix I) which include a listing of babies identified with missed or unknown screening for hospitals to reconcile with their own data and correct if appropriate. While some hospitals are diligent in comparing and correcting their data, other hospitals do not verify the data for every child. To improve the data quality during the funding cycle, for all cases of "unknown" screening results, the Research Scientist and Information Technology Specialist will contact the hospitals, have them review the charts of children with unknown screening status, and ensure screening status has been documented.

For children born in 2007 and not screened by one month of age, 47% were from one hospital that had a breakdown of their single piece of hearing screening equipment. They were unable to get timely repair or replacement and despite referring babies for outpatient screening at other facilities, over half were never screened. The EHDI program always discusses equipment failure plans during annual site visits. Previously, the EHDI program ran hospital-specific statistics only on a quarterly basis. In 2007, the Research Scientist included a process to check current screening and refer rates every time the weekly EBC files are imported. If a sudden change is noted, the hospital is contacted immediately to determine the cause and verify that steps are in place to ensure that missed babies are screened. This process will be continued during the new funding cycle. Additionally, the EHDI program will incorporate a case-by-case review of missed babies with each hospital and the EHDI staff will review hospital or system improvements that could prevent missed screening.

With the EHDI administrative rules in place in New Jersey, it is each hospital, rather than the DHSS EHDI program, that is responsible for ensuring the completion of outpatient follow-up. The rules require that hospitals give families the screening results, and for those that need follow-up testing, hospitals must provide a list of outpatient testing locations; must make at least one reminder contact, via telephone or mail; and must report failed contact attempts or other indications if follow-up has not occurred.

Despite this regulatory requirement to report children as lost to follow-up, most hospitals have some children where follow-up status remains undocumented. Hospital site visits and technical assistance sessions beginning in year two will include a case-by-case review of these children. Hospitals will be assisted in assuring that lost to follow-up forms have been submitted when appropriate. Targeted interventions will be developed when more complete information is available on reasons for lost to follow-up.

Another area for improvement will be in the identification and management of children that have had only partial follow-up testing done. This includes children that failed an outpatient rescreening or had transient conductive hearing loss during follow-up testing, with no further audiologic evaluation completed. For children born in 2006, 10.1% of children with follow-up testing had incomplete follow-up. Starting in year two, for these children, follow-up contacts to pediatricians will be implemented.

Pediatrician education on ensuring follow-up is an ongoing need. The American Academy of Pediatrics (AAP) EHDI Chapter Champion, Dr. Michael Graff, continues to educate pediatricians. The EHDI program and Dr. Graff have collaborated with the DHSS Newborn Biochemical and Genetic Screening Program (NB&GS) and the New Jersey AAP chapter on the development of a Web-based continuing medical education program on newborn screening in New Jersey. This learning opportunity is expected to be available to pediatricians during 2008. The EHDI program will encourage pediatricians to participate in this and other EHDI educational efforts.

Education for otolaryngologists will be a new initiative during this funding cycle. The program's Hearing Evaluation Council includes membership of an otolaryngologist, Dr. Jed Kwartler, who has agreed to assist the program in education targeted at the otolaryngology community. Educational efforts will focus on the EHDI program goals and reporting requirements relevant to these physicians. Additionally, in year two and three of the funding cycle, the Information Technology Specialist will develop a survey, database elements, and reports to incorporate pediatric otolaryngologists into the New Jersey Pediatric Hearing Health Care Directory, since it currently includes primarily audiologists and hearing aid dispensers.

Audiology education also remains a critical focus to ensure timely, accurate and complete data in the EHDI tracking system. The EHDI Audiologist will continue to hold routine site visits and/or conference calls with both hospital and non-hospital based audiology facilities. The audiologist will also provide essential updates to the audiology community via an email distribution list maintained by the EHDI staff. The audiologist will discuss changes in the Joint Committee on Infant Hearing (JCIH) 2007 Position statement recommendations specific to components of audiologic evaluation and surveillance of children with risk indicators for progressive/late onset hearing loss.

<u>Goal 2</u>: Enhance the capacity of the New Jersey EHDI surveillance system to accurately report on the status of every occurrent birth throughout the EHDI process for the purpose of evaluating the progress toward the National EHDI goals.

<u>Obj. 2.1</u>: Throughout the funding cycle, every February, May, August and November, distribute hospital-specific quarterly reports which will include unduplicated individual data on all children not passing initial screening and review performance with each hospital during annual site visits/technical assistance conferences.

<u>Obj. 2.2</u>: Incorporate hearing screening and risk indicator data collected in the Web-based EBRS into the EHDI program database and quarterly reports by June 30, 2011.

<u>Obj. 2.3</u>: Annually submit screening, follow-up, and early intervention data as part of the National CDC EHDI Hearing Screening and Follow-up Survey, and demonstrate annual improvements in rates of timely screening, follow-up, and early intervention enrollment.

<u>Obj. 2.4</u>: Annually, program staff will attend National EHDI meetings to share and learn strategies for measuring and achieving National EHDI goals.

<u>Methods for Goal 2</u>: The EHDI program will monitor hospital performance by distributing and reviewing quarterly reports (Appendix I). These include statistics comparing each hospital to statewide performance, as well as detailed lists of children needing additional follow-up and potential EBC errors for review. During the upcoming funding cycle, reports will be enhanced to include hospital-specific statistics on the timeliness of diagnosis and EI enrollment.

While the EHDI program expects to benefit from the EBC system update, conversion to a new system will require a total redesign of the current data flow and report programming. The quarterly reports, annual CDC data request, and other routinely calculated statistics are all based upon the current EBC file layout and content. As such, the Research Scientist will need to reprogram all reports to utilize the revised EBRS data in order to continue to provide feedback to the hospitals and to submit statewide statistics to CDC and other entities. The timeline for this activity will be in accordance with the roll-out of the revised EBRS system, but is anticipated to occur in the third year of the funding cycle.

The current and developing linkages with EI are an essential element of providing complete data for the annual CDC data request and documenting progress toward the goal of EI enrollment by six months of age. The EHDI program will continue semi-annual data matching protocols with EI in order to continue to track status of children with hearing loss through EI enrollment.

EHDI staff have attended every National EHDI meeting, which has allowed for: the adoption of best practices used in other states, the opportunity to compare New Jersey’s performance to other states’ progress toward National EHDI goals, and a chance to share our own successful ideas with others. Funding from this cooperative agreement will be used to send the Program Manger and the two CDC-funded EHDI staff to each annual meeting.

Goal 3: Develop and enhance the capacity of the EHDI program to integrate the EHDI system with other State screening, tracking, and surveillance programs that identify children with special health needs.

Obj. 3.1: By June 30, 2010, develop and submit a procedure for interstate data sharing with bordering and non-bordering states.

Obj. 3.2: By June 30, 2009 implement NJIIS-EHDI module enhancements to incorporate Joint Committee on Infant Hearing (JCIH) 2007 Position Statement recommendations.

Obj. 3.3: During each year of the funding cycle, conduct at least three training sessions for new NJIIS-EHDI module users.

Obj. 3.4: In February, May, August, and November of each year of the funding cycle, complete quarterly cross-matches of EHDI follow-up reports and SCHS Registry data to ensure all children with hearing loss are appropriately documented.

Obj. 3.5: By December 31, 2010, in collaboration with the SCHS Registry program, ensure the new Birth Defects Registration System (BDRS) is capturing data on diagnosis, amplification, and case disposition for all children with hearing loss.

Obj. 3.6: Semi-annually throughout the funding cycle, conduct a data match to EI system files to compare and reconcile data on children with hearing loss and identify reasons given for non-enrollment in EI.

Activities for Goal 3: One barrier to documentation of hearing screening, follow-up, and diagnostic testing status is cases where children born in New Jersey reside out of state. The EHDI program has drafted a procedure for cross-border deliveries with neighboring Pennsylvania that will improve the tracking of babies that are born in one of these states, but reside in the other. Full implementation of this procedure is targeted for 2008. A cross-border procedure for New York is more challenging since New York's Department of Health currently does not collect individually identifiable data and tracking is handled at the hospital level. A plan will be developed and implemented during the funding cycle to make contacts with the EHDI staff at the New York hospitals most likely to work with cross-border families. Though Delaware is a bordering state, it accounts for very few (~25) cross-border births each year. A small number of deliveries to New Jersey residents will occur in other states as well, as will some New Jersey births to residents of other states. An additional data sharing plan to address these scenarios will also be developed.

Despite the successes of the NJIIS-EHDI interface in improving the timeliness, quality, and accessibility of hearing evaluation data, there remain some areas for improvement in this system. The current NJIIS-EHDI data collection form requires some modifications to become compliant with the JCIH 2007 Position Statement. The progressive/late-onset risk indicator list on the form in the NJIIS will be updated to reflect the new JCIH Statement, and references to follow-up for these children "every 6 months" will be changed to "by 24-30 months." The Research Scientist will collaborate with NJIIS staff to implement these system updates and the Information Technology Specialist will assist in beta testing of the NJIIS-EHDI revisions.

While many audiology providers have already been trained on using the NJIIS, there continue to be new staff hires and others that need training on this system. Therefore, this cooperative agreement will be used to support the Research Scientist and the Information Technology Specialist in conducting ongoing training sessions for NJIIS-EHDI users.

Improvements in data linkages with the SCHS Registry and the EI program will also be a focus of the funding cycle. The SCHS Registry program is currently implementing a new Birth Defects Registry System (BDRS) which will be a Web-based system, replacing a stand-alone computer system that is nearly twenty years old. The BDRS will have greatly expanded capabilities that will permit secure electronic registration of children by hospitals, medical providers, Case Management Units (CMUs), and audiologists. It will include, for the first time, information on services provided to children by the CMUs. This will allow tracking of national EHDI performance indicators such as the percent of families that refuse EI services, and the percent of children with hearing loss referred for ophthalmology, otolaryngology and genetic evaluations. The CMU module will include documentation of amplification choices including hearing aid fitting and cochlear implants. The BDRS is being developed through a memorandum of agreement with Rutgers, The State University of New Jersey. The expectation is for beta testing to begin in July 2009 and pilot testing and full roll-out to occur in 2010.

The current Statewide EI data system was implemented in 2004. County units submit paper forms to four Regional Early Intervention Collaboratives (REIC) and the REICs input the data into EI's System Point of Entry (SPOE) database. A procedure for matching children in the SCHS Registry and in EI with a diagnosis of presumptive eligibility for EI enrollment was developed in October 2005. The matching procedure was modified after evaluating the findings from several attempts, and continues to be refined. Compared data is output as: "perfect" matches, "close" matches, and "unmatched." Close matches, such as identical names with slightly different birth dates, are manually reviewed to determine if they represent the same child. The unmatched cases are also manually reviewed, to identify any additional cases where adjustments to the programming logic would allow electronic matches. After the process is complete, the county CMUs will be asked to review the unmatched lists and provide feedback. For children with a registered diagnosis but not in EI, CMUs are asked to supply the reason for non-enrollment (parent refused EI, family moved, unable to contact family, etc.). For those in EI, but not known to the SCHS Registry, CMUs are asked to submit SCHS Registration forms, since SCHS Registry rules require the CMUs to register children. The findings of this match for children with hearing loss are available to the EHDI program in order to track children though enrollment in EI services.

The most recent EI match was done in January 2008, with 131 children identified with hearing loss that were in both systems. Of these, 105 matched exactly in both files and the remaining 26 were "close" matches that were confirmed upon manual review. Of the matched children, 48% were referred to EI by six months of age. The proposed next step of CMU investigation, to determine the reason for unmatched cases, has not yet been implemented and will be a focus of the upcoming funding cycle. The goal is to improve the matching process, identify reasons why children are not enrolling in early intervention, and work to remediate any barriers to enrollment.

Collaborative Efforts

A long-standing and strong relationship exists with the Bureau of Vital Statistics and Registration (BVSR), in the Office of the Commissioner. This unit ensures that EBC data is provided to the EHDI Program. Included in this data file are the initial screening results and risk indicators for hearing loss. The BVSR is including the EHDI staff in the planning process for development of the planned Web-based EBC system that will be designed using National Association of Public Health Statistics and Information System (NAPHSIS) guidelines and the U.S. Standard Certificate of Live Birth issued by the CDC.

NJIIS staff has been enthusiastic about the inclusion of hearing information in their tracking system since it can benefit them through increased provider participation. Continuation of the NJIIS-EHDI interface and enhancements to the current system are part of the work plan for the funding cycle.

Staff from EHDI and the programs responsible for the SCHS Registry, the CMUs, and EI program all report to the same Service Director and experience excellent communication and cooperation, meeting regularly, and partnering on projects. For example, the EHDI audiologist has presented at regional and local meetings of case management supervisors and EI service coordinators. The procedure to use data from CMU and EI systems to track children with hearing loss through EI enrollment will be an ongoing collaborative effort.

Collaboration with the Division of the Deaf and Hard of Hearing (DDHH) in the

Department of Human Services has included giving a presentation at their annual Statewide meeting, EHDI staff membership on the Deaf and Hard of Hearing Advisory Council, collaborating on a parent education brochure, and co-sponsoring a biennial Family Learning Day conference – a one-day program for parents of children with hearing loss.

The EHDI Program has also established successful working relationships with staff from the Department of Education (DOE). The Coordinator of Programs/Services for Children who are Deaf/Hard of Hearing presented at an EHDI panel discussion for audiologists in May 2007 and has met with EHDI staff to discuss DOE statistics on children with hearing impairment and resources for parents.

Annual EHDI site visits to all maternity hospitals and audiology practices have been very successful in producing an atmosphere of familiarity, cooperation, and mutual support for the goals of the EHDI program.

The EHDI program has partnered with the State American Academy of Pediatrics (AAP) Chapter on several initiatives. Dr. Michael Graff, the EHDI Chapter Champion, attends National EHDI meetings, has given many local presentations, and participated in the previously noted web-based continuing medical education course to be launched in 2008.

New Jersey collaborates with the CDC and other states through participation on CDC EHDI conference calls, including the Executive Committee, Data Committee, Diversity Committee, Research Committee and Family Issues Committee calls. EHDI staff have given or co-authored seven national EHDI meeting presentations since 2002. In 2008, the Information Technology Specialist presented a poster on “The New Jersey Pediatric Hearing Health Care Directory.” In 2007, the Research Scientist presented “Utilizing a Statewide Immunization Registry for EHDI Tracking and Reporting” and the EHDI Audiologist co-authored “NJ Family Learning Day – A Collaborative Approach to Family Support” which was presented by a colleague from the state Parent-to-Parent support program.

The New Jersey EHDI program currently receives funding from the Health Resources and Services Administration (HRSA) Universal Newborn Hearing Screening grant, which supports salaries for two EHDI staff dedicated primarily to follow-up activities, the Public Health Consultant - Nursing and 35% of the salary for the Information Technology Specialist.

The Hearing Evaluation Council has also been instrumental in developing and maintaining collaborative relationships, as it is comprised of representatives from all major stakeholders. The universal hearing screening legislation mandates the existence of the Council and stipulates membership, appointed by the Commissioner, 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. Since inclusion of parents of children with hearing loss is not in the law, nominees meeting this desired characteristic were recommended under the category of concerned citizen, and some members qualifying under other criteria also have a child with a hearing loss. The Council has convened quarterly since December 2005, with the initial two-year appointment period recently ending. Continued appointments and new candidates to replace members who resigned their seats were recently approved by the Commissioner and the new Council met in April 2006.

Program Capacity

The EHDI program is part of the New Jersey Department of Health and Senior Services, Division of Family Health Services (FHS), headquartered in Trenton, New Jersey, which has sufficient space, equipment, and facilities to house this project. FHS works to improve the health, safety, and well being of families and communities in New Jersey and consists of four Offices (Medical Director, MCH Epidemiology; Primary Health Care; Procedural Safeguards for Early Intervention; and Women's Health) and four service units: Maternal, Child and Community Health Services (MCCH); Women, Infants, and Children Services (WIC); Chronic Disease Prevention and Control Services (CDPC); and Special Child Health and Early Intervention Services (SCHEIS). Programs supporting the EHDI objectives are located together both physically and organizationally. 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 (FCC), and Early Intervention System (EIS) (see organizational charts, Appendix F).

EIM is responsible for maintaining the EHDI program and the SCHS Registry. NB&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 condition. FCC is responsible for the 21 county-based CMUs 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. The CMUs are the single point of entry in each county for Part C, providing service coordination for this system.

New Jersey's prior experience with Early Hearing Detection and Intervention is long and successful. In 1977, New Jersey's first law and rules addressing newborn hearing screening required that all newborns be assessed for risk factors for hearing loss and reported to the DHSS. In May 2000, revised rules required an electrophysiological hearing screening on all babies with a risk factor for hearing loss, and universal newborn hearing screening was implemented in with the new law effective in January 2002. Current administrative rules, adopted in December 2005 were written to more specifically detail the roles of hospitals, audiologists, and pediatricians and also very precisely outlined the elements required for each hospital's EHDI procedures, such as requiring written notification of screening results be given to both the parent and the pediatrician, and requiring that hospitals make at least one follow-up contact with the parent. These rules establish the current JCIH Position Statement as the standard for determining risk indicators for progressive/late-onset hearing loss and the appropriate monitoring intervals for children with these conditions. The rules continued the requirement for reporting outpatient audiologic follow-up and also implemented mandatory reporting when children are considered to be lost to follow-up.

The EHDI program has had significant positive prior experiences in collaborating with other DHSS units to improve EHDI reporting. In 2004, the EBC fields related to hearing screening did not capture ear-specific results. The EHDI program partnered with BVSR to update the EBC system, assisting with beta testing, training, and installation of the revised EBC system. The collaboration with the NJIIS has also been a very beneficial and successful process. In just one year after obtaining a signed memorandum of agreement between the units, the NJIIS-EHDI interface had been developed, beta tested, and was operational. The system is now the primary mechanism for documentation of all outpatient audiologic testing and has received very favorable reviews from its end users.

Since enactment of New Jersey's universal newborn hearing screening legislation in 2002, the EHDI program has had significant success in tracking and improving progress toward EHDI goals. As noted in the quarterly report sample (Appendix I), rates of screening and timely follow-up have consistently improved each year through the efforts of the EHDI program. Early diagnosis of hearing loss and timely enrollment in early intervention services are also showing consistent improvement over time. These statistics provide evidence of the capacity of New Jersey's EHDI program to track and monitor hearing screening and follow-up.

Staffing and Management Plan

Both the DHSS Division of Family Health Services (FHS) and SCHEIS have a long and successful history in designing and developing systems of services for children with special needs. SCHEIS personnel have expertise in the handling of large, complex, and confidential databases and in analyzing data using a variety of data management software. Two positions, the Research Scientist and the Information Technology Specialist, will be funded with this cooperative agreement and are devoted 100% to the EHDI program. Job descriptions are found in Appendix J.

The maintenance and enhancement of the EHDI tracking system is the responsibility of the Research Scientist, Kathryn Aveni, RNC, MPH. She will ensure collection of demographic, screening, diagnostic, referral, intervention, and follow-up data. She will be responsible for linking the EHDI system to the EBRS, NJIIS, SCHS Registry, and EI data and will investigate other data linkages. She conducts data analysis and produces all EHDI data reports.

Karyn Dynak, BA, the Information Technology, will be funded 65% from this cooperative agreement, with the remainder of her salary funded by a HRSA Universal Newborn Hearing Screening grant. She has developed and maintains a database of pediatric audiologic providers used to create the New Jersey Pediatric Hearing Health Care Directory. She conducts NJIIS-EHDI training sessions for new users and assists with data report production and quality assurance efforts. She also provides technical assistance and conducts site visits for hospitals and focuses on follow-up issues, including outreach to pediatricians.

Additional program, managerial, and administrative staff support the efforts and results of the tracking system. Brief resumes (Appendix K) and organizational charts (Appendix F) are attached. All EHDI staff have been in their current positions since at least 2004, giving the program a strong ability to work as a team and with solid EHDI knowledge and experience. These individuals dedicated to the EHDI program and are funded through the MCH Block

Grant or the HRSA Universal Newborn Hearing Screening grant:

Nancy Schneider, MA, CCC-A, FAAA is the EHDI Audiologist and brings over 25 years of experience as a pediatric clinical audiologist, including implementing a universal newborn hearing screening program at one New Jersey hospital. As the liaison to the audiology community, she is responsible for educating audiologists about timely and complete reporting of outpatient exams, audiologic evaluation protocols, and national guidelines. Her time is 100% dedicated to the EHDI program.

Linda Biando, RN, MSN is the Public Health Consultant, Nursing for the EHDI program and has many years of experience with the SCHS Registry program. Her duties include conducting hospital visits and providing technical assistance to hospitals, abstracting medical records, ensuring that children with a hearing loss are appropriately registered, and reconciling discrepancies in hearing loss diagnoses in the SCHS Registry and EI database as compared to the EHDI outpatient exam reports. Her time is 100% dedicated to the EHDI program.

Tracey Justice is the Senior Clerk for the EHDI program and is responsible for the data entry of the outpatient follow-up forms, in addition to other clerical needs of the program. Her time is 100% dedicated to the EHDI program.

Leslie Beres-Sochka, MS, Program Manager and Principal Investigator, has primary responsibility for the Early Identification and Monitoring (EIM) program, including the EHDI program and the SCHS Registry. She has skills in management of large-scale studies, as well as expertise in database management, data analysis, surveillance, and data dissemination. Approximately 25% of her time is dedicated to EHDI.

Evaluation Plan

Performance on each objective and continuous program assessments will be evaluated as detailed in Appendix H, and includes documenting screening, follow-up, and EI enrollment rates; counting hospital visits, NJIIS-EHDI trainings, and other meetings; and monitoring completion of data system interfaces. Performance on non-statistical objectives, such as collaboration efforts, will be monitored by the Research Scientist and Program Manager. Modifications to the EHDI program will be made as necessary, based upon these evaluations.

Quarterly reports (Appendix I) will continue to be provided to all birthing hospitals, allowing both the EHDI program and hospitals to monitor key objectives and trends. With these reports, hospitals also receive detailed listings of records with suspected data entry errors, such as those where the reason given for outpatient testing is a previous failed screen but the inpatient results are documented as passing. For any case of diagnosed hearing loss where the inpatient results were noted as a pass, the EHDI staff contacts the birth hospital and/or audiologist to determine if the baby did, in fact, pass inpatient screening and has a late-onset hearing loss, or if the inpatient results were recorded in error. The proposed "zero tolerance" policy for unknown inpatient testing status, case-by-case review of all babies not screened by discharge or with unknown follow-up status, and follow-up on incomplete audiologic exams will also enhance data quality.

Comprehensive annual reports including the national EHDI goals and performance indicators are routinely presented to the EHDI Hearing Evaluation Council. Data on screening, diagnosis, and EI enrollment is calculated and submitted by New Jersey for the national annual CDC data request. Summary statistics are also shared with the regional Maternal-Child Health Consortia for review by their quality assurance committees. Obtaining more detailed information for these reports about case disposition, amplification status, and reasons for lack of EI enrollment will be a focus of the upcoming funding cycle.

Comparative analyses using the EHDI database have been conducted, such as documenting that infants not screened before discharge are less likely to receive outpatient follow-up as compared to babies that are tested and refer, validating the importance of ensuring a screening attempt before hospital discharge. The EHDI database has been used to analyze performance on EHDI objectives for racial, ethnic, linguistic and geographic subgroups. This data was presented by the Research Scientist at the 2006 national EHDI meeting. This analysis revealed that, in many cases, hospital of birth was more predictive of follow-up compliance than any demographic predictor – indicating a continued need for emphasis on hospital technical assistance as a focus of the EHDI program's efforts to improve performance. Additional detailed analyses of EHDI data will continue through the funding period.

Quality Assurance of the data is assessed at many points throughout the EHDI data process. Both the EBC system and the NJIIS-EHDI interface contain built-in error checks, such as the inability to enter a testing date that is prior to the child's date of birth. The NJIIS-EHDI module has been particularly helpful in ensuring data quality since the audiologists can not submit the form electronically if mandatory fields are blank or conflicting information has been entered. Use of the NJIIS also enhances data quality since demographic data from the NJIIS system is automatically entered into the hearing report form, decreasing data entry time and reducing potential typographical errors. The information can be edited as necessary, such as for a change of address. Ongoing data matches with the SCHS Registry and EI programs also contain a quality assurance component. Since "close" matches are manually reviewed, many typos in a child's name or birth date are identified and corrected.

In addition to quality assurance activities and evaluation of progress on individual goals and objectives, the New Jersey EHDI program maintains a focus on attaining the national EHDI goals of screening by one month of age, diagnosis by three months of age, and early intervention by six months of age and will continually evaluate progress toward these goals.