Program Narrative

Accomplishments:

EHDI staff have modified the provision of technical support to hospitals, with regional group meetings replacing the previous individual hospital site visits. This new format has allowed for a lively and informative sharing of ideas between New Jersey hospital EHDI programs and provided the opportunity for hospitals to learn best practices directly from those who have been successful with those activities. EHDI staff are also conducting more complete and detailed case reviews for all instances of children lost to follow-up to improve follow-up rates. In some instances, this case review has identified situations where outpatient follow-up occurred, but was not reported to the EHDI program. The reviews have allowed the opportunity to track down missing reports and more accurately represent follow-up rates. More intensive outreach and follow-up of cases with individual pediatric providers has also been conducted, along with educational presentations to physicians, audiologists and other health care professionals.

Activities are well underway on the two subgrants of the supplemental funding award received September 1, 2009. The first was to fund case managers to conduct follow-up calls to parents and physicians as a supplement to the hospitals' mandated single contact attempt. The case managers were trained in early October and contacts commenced in mid-October. The availability of a bilingual (Spanish/English) case manager and utilization of a telephone-based language translation service is an important step in ensuring parents are adequately educated about the need for hearing follow-up evaluations. The other supplemental funding objective is also in progress to provide funds to several Federally Qualified Health Centers (FQHCs) to

purchase screening equipment and conduct rescreening. To date, a mini-grant application packet was distributed and three FQHCs have submitted applications for funding.

No significant barriers to meeting the goals and objectives of this grant have been encountered during the current fiscal year to date.

Progress on Goals and Objectives:

Note that Goals 4, 5 and 6 are from the Summer 2009 supplemental funding application.

Goal 1: By March 31, 2012, reduce the rate of infants lost to follow-up between hospital discharge and outpatient screening to no more than 10%.

Objective 1.1: Rates of infants receiving timely follow-up after referring on inpatient screening will rise annually during the funding cycle.

Rates of timely follow-up have shown consistent improvement, including during the first part of 2009. Appendix 1 shows current statewide data in the format used in semi-annual EHDI reports distributed to all New Jersey hospitals. The rate of any follow-up for infants that missed or referred on inpatient screening rose from 66.8% in 2008 to 69.3% for the first quarter of 2009. The rate of timely (by three months of age) follow-up rose from 56.3% in 2008 to 59.3% for first quarter 2009. Note that follow-up data for the second quarter of 2009 noted on Appendix 1 is still incomplete. It is anticipated that as additional reports are received, the upward trend will continue.

The EHDI program held regional meetings for hospital EHDI staff in September and October 2009. In prior years, the EHDI program has conducted an individual performance review with each hospital, either in person or via teleconference. This year, three programs were held in the northern, central and southern locations in the state, with each hospital sending at

least one representative to one of the three meetings. At each meeting, two hospitals provided an overview of their own EHDI processes and focused on how they have overcome challenges. Also included was a roundtable discussion of several topics including strategies for improving follow-up. The meetings were very well received and included much sharing of information among peers. The meetings were held on September 25th with 24 attendees, September 30th with 44 attendees, and October 7th with 28 attendees.

Individual teleconferences with each hospital began on October 19, 2009 and will continue through April 2010. As part of these conference calls, the EHDI team will continue a case review process that started in 2008, where each instance of infants that missed or referred on initial screening with no follow-up reported are reviewed to determine if results were documented correctly, if required follow-up contacts were made, and to review potential areas for improvement in follow-up.

Objective 1.2: By March 31, 2012, all New Jersey birthing hospitals will utilize at least one of the National Institute for Children's Healthcare Quality (NICHQ) strategies, and/or will adopt other strategies to improve in follow-up rates.

As noted for Objective 1.1, discussion of effective follow-up strategies, including several of the NICHQ Learning Collaborative suggestions, were reviewed in the roundtable discussions at the regional EHDI meetings. A complete tally and review of which NCIHQ strategies are being used at each hospital is part of the agenda for their teleconference calls (see Appendix 2 for the worksheet being completed by each hospital). During Fall 2008 site visits and conference calls, discussion of these strategies revealed that most hospitals were already using at least one of these recommendations.

Objective 1.3: Annually educate at least 100 health care providers about their requirements for reporting outpatient rescreening.

As noted in Objective 1.1, 96 health care professionals involved in hospital EHDI programs attended the regional EHDI meetings. These participants included audiologists, physicians, nurses, administrators and clerical staff. The Research Scientist presented at a June 2009 statewide genetics conference focused on hearing loss and auricular anomalies that had 74 attendees, including 27 physicians and eight audiologists. The EHDI audiologist met with seven audiologists at three facilities to conduct training on the EHDI interface in the New Jersey Immunization Information System (NJIIS), as well as to review EHDI reporting requirements and Joint Committee of Infant Hearing (JCIH) updates. This EHDI module in the NJIIS is the primary mechanism for data entry of outpatient hearing evaluation results. The Research Scientist conducted five additional NJIIS trainings for 29 non-audiologist users. In June 2009, the EHDI audiologist began a series of teleconferences for audiologists and hearing aid dispensers focusing on a variety of subjects. The first, with 27 registrants, was an overview of the EHDI program, including a review of the reporting requirements.

Goal 2: By March 31, 2012, reduce the rate of infants lost to follow-up between outpatient screening and diagnostic testing to no more than 10%.

Objective 2.1: Rate of diagnostic testing after a refer result on outpatient screening will increase annually during the grant cycle.

Data to calculate the rates for completion of diagnostic testing after an outpatient screening refer is still incomplete for the current grant year; however, several activities toward

improving this outcome are underway. A teleconference for audiologists covering the NICHQ strategies for improving timely diagnostic audiology services (i.e., making two appointments, fax-back to the primary care provider), is being planned for January 2010. New efforts to ensure follow-up after failed outpatient rescreening are included in the activities of our supplemental funding (see Goals 4 and 5 below). When a failed rescreening is reported to the EHDI program, it is usually assumed that the screener will make appropriate referrals for diagnostic testing. The Research Scientist has included programming in the EHDI database that will flag records of children that have not had additional follow-up after a refer rescreening result within the expected time frame. These records are being included in the cases for parent contact that are being conducted with the subgrantee agency.

Objective 2.2: Provide the health care community with information to ensure timely and appropriate referrals for diagnostic audiologic evaluation.

The New Jersey Pediatric Hearing Healthcare Directory was updated in July 2009. Annually, audiologists and hearing aid dispensers in New Jersey are asked to verify their current listing and new facilities are added. This resource enables physicians and families to locate facilities in their area that have the required diagnostic services.

The Public Health Consultant, Nursing (PHCN) has been targeting specific pediatric provider offices for education and outreach. A list of providers that were thought to be the primary care provider for the greatest number of children with no follow-up was generated. The PHCN has contacted four of these offices to date and three agreed to review the list of children with no follow-up to determine their screening status. One center learned through this contact that the hospital hearing screening results could be obtained from the New Jersey Immunization Information System (NJIIS), so they can more easily monitor screening results and follow-up. In

addition, the PHCN has scheduled site visits in October and November for two physician offices who have been identified as sites where outpatient hearing rescreening is being conducted in the physician offices, but required reports have not been received. The reporting requirements will be reviewed, along with a discussion of the EHDI goals and the expectations for timely follow-up and additional referrals if infants do not pass their rescreening. Additional visits will be scheduled as similar physician practices are identified.

The EHDI audiologist presented at a statewide conference in June 2009 that was attended by 56 attendees, including physicians, audiologists and various other health care professionals. As noted for Objective 1.3, the EHDI teleconference series for audiologists and hearing aid dispensers is an ongoing effort at educating providers about appropriate follow-up. Eleven calls have been held or are currently scheduled for the remainder of 2009. Topics include Department of Education services for hearing impaired children, parent support services, techniques on bone-conduction ABR testing, and a review of EHDI-program data. At least four teleconferences for early 2010 are currently being planned, including one on NICHQ strategies for decreasing loss to follow-up between referred rescreening and diagnostic testing. Education for otolaryngologists is currently being developed as a teleconference entitled "What New Jersey ENTs Need to Know About Newborn Hearing Screening."

In September 2009, the research scientist and EHDI audiologist gave a presentation to approximately 35 professionals who work for managed care companies that provided coverage for New Jersey's Medicaid population. The intent of the meeting was to increase the availability of information about the hearing screening and follow-up status for their members, and to ensure the managed care staff were able to aid in the process of ensuring timely and appropriate follow-up for their members.

Goal 3: By March 31, 2010, reduce the rate of infants lost to follow-up between hearing loss diagnosis and early intervention enrollment to no more than 10%.

Objective 3.1: Rate of early intervention enrollment after a hearing loss diagnosis will increase annually during the grant cycle.

The semi-annual data match with the Early Intervention (EI) program is currently just beginning. The EHDI program is scheduled to meet with the New Jersey Part C Coordinator in November 2009 to discuss a process for obtaining parental consent to release information to the EHDI program upon enrollment. Though data is already shared routinely, this will provide more timely access to information about EI enrollment status. Additionally, a meeting is scheduled for December 2009 with the Superintendent of New Jersey's School for the Deaf to discuss obtaining parental consent for data sharing. Previously this school was a designated provider of EI services through the Part C program, but in 2008 did not renew this contract, though the school still has an infant-toddler program. Obtaining parental consent will allow the EHDI program to document this enrollment in non-Part C EI services.

Objective 3.2: Provide health care community with information to ensure timely and appropriate referrals for diagnostic audiologic evaluation.

As noted for Objective 2.2 several educational offerings targeted at physicians and audiologists have been held. Additionally, the EHDI program will hold a teleconference for the county-based Special Child Health Services case management units and for Early Intervention service coordinators in early 2010 to provide information about ensuring timely audiologic evaluation and Early Intervention enrollment.

Goal 4: Reduce the rate of infants lost to follow-up between hospital discharge and outpatient screening by at least 7% annually, to reduce the lost to follow-up rate to no more than 10% of referred infants each year.

Objective 4.1: Annually during the funding cycle, the bilingual consultant will make follow-up contacts to an average of 15 infants per week.

Upon receipt of the supplemental funding, revisions were made to an existing Department of Health and Senior Services grant to the Mercer County Special Child Health Services Case Management Unit (Mercer CMU), to add staff hours for three case managers to conduct follow-up phone call to parents and physicians. One of the three staff members is bilingual and contacts all the families identified as Spanish-speaking. Additionally, access to a language line service was made available to the Mercer CMU staff. A full-day training session was conducted on October 5, 2009 to provide background information about the EHDI program, review contact protocols, role-play various scenarios, and train staff on the NJIIS interface for reporting purposes. An initial case list was provided and staff have initiated phone calls. Additional cases will be provided to the Mercer CMU on a weekly or bi-weekly basis.

Objective 4.2: By March 31, 2012, four FQHCs will be conducting hearing rescreening, with at least 400 children screened annually at FQHC sites.

A mini-grant application was developed to allow funding of $25,000 to each of three FQHCs for purchase of equipment and supplies, and staff time and training. The applications were released in late September to the three FQHCs that have the highest annual case load of children under age one. Grant applications were due mid-October and are currently being reviewed and in the process of conferring funding to the agencies. Expectations are that equipment will be purchased by January 2010 with screening to begin by February 2010. The

provision of funding is contingent upon the FQHCs' agreement to provide rescreening services at no charge to the families. They are able to bill for the service if the family has insurance, but will not assess co-pays or balance bill if insurance does not fully cover the cost of rescreening. For Year 2 of the funding cycle, two additional facilities will be provided money through the mini-grant process, and the current facilities will receive funds to cover their ongoing supply and staff costs that are not recouped through billing.

Goal 5: Reduce the rate of infants lost to follow-up between rescreening and audiologic diagnosis by at least 10% annually, and reduce the lost to follow-up rate to no more than 10% of referred infants each year.

Objective 5.1: Annually during the funding cycle, the bilingual consultant will make follow-up contacts to an average of 5 infants per week.

As noted for Objective 4.2, Mercer CMU staff have initiated parent contacts for both infants that referred on inpatient screening with no additional follow-up and those who referred on rescreening but have not had diagnostic testing completed. These calls began in late October, so the average number contacts and effectiveness can not yet be determined.

Goal 6: Reduce the rate of infants lost to follow-up between diagnosis and early intervention by at least 3% annually, and reduce the lost to follow-up rate to no more than 15% of referred infants each year.

Objective 6.1: Rate of early intervention enrollment after a hearing loss diagnosis will increase annually during the grant cycle.

Supplemental funding activities for this Objective, to pursue opportunities to provide EI services via telehealth options, are slated for years two and three of the funding cycle. As noted in Goal 3, data matching and education to the Early Intervention and Case Management professionals will also contribute to achieving this goal.

Current Staffing:

No staffing changes have occurred during the current funding year. Achieving the goals and objectives of this grant will be the primary full-time responsibility for one current EHDI staff member, to be funded at .85 FTE through this grant with the additional .15 FTE paid from Centers for Disease Control and Prevention funding. Linda Biando, RN, MSN is the Public Health Consultant - Nursing funded by this grant and has 20 years of experience with New Jersey Special Child Health Services. Her current duties include conducting hospital visits, providing technical support to hospitals, abstracting medical records, conducting outreach to physicians, and ensuring that children with a hearing loss are appropriately registered and enrolled in Early Intervention services.

Three other full time EHDI staff members contribute to the achievement of the program's goals: Nancy Schneider, MS, CCC-A, FAAA is the audiologist for the EHDI Program and brings over 20 years of experience as a pediatric clinical audiologist, including implementing one New Jersey hospital's universal newborn hearing screening program. As the liaison to the audiology community, she is responsible for establishing audiologic protocols and guidelines and is educating audiologists about the need for timely and complete reporting of outpatient exams. She will assist the FQHCs in selecting screening equipment, will provide training on conducting rescreening and will provide oversight and competency review for screenings conducted at these

sites. The specific FQHC staff that will be involved in the activities of this grant will be determined after receipt of funding and the designation of the appropriate sites. Kathryn Aveni, RNC, MPH is the Research Scientist 1 for the EHDI Program and has experience in nursing, public health and data analysis, and program management. She is responsible for the creation, enhancement and maintenance of the EHDI data system and she provides grant management and administrative oversight for the EHDI Program. Tracey Justice is the Senior Clerk for the EHDI Program and is responsible for the data entry of outpatient follow-up forms in addition to other clerical needs of the program.

Three staff at the Mercer CMU are providing services through the supplemental funding arrangements, each providing a long history of assisting families of children with special health needs. Deborah Medvedik, MSW, LSW has served as the Unit Coordinator for the Mercer CMU since 2005 and has been a staff member at this Mercer CMU since 1997. She had five years of additional social work experience prior to joining the case management unit staff. Elizabeth Parry, RN, BSN, has been a nurse case manager with the Mercer CMU since 1990, after twelve years of experience in clinical nursing and school nursing. The bilingual consultant, Mona Elkin, RN, BSN, has ten years of clinical nursing experience, followed by employment as a service coordinator at the Mercer CMU since 2001.

Technical Assistance Needs:

The New Jersey EHDI program will require technical assistance from HRSA in the implementation of the objective piloting telehealth for early intervention services. Since the EHDI program has no prior experiences in this area, we would appreciate being connected with states that have had successful attempts at implementing telehealth in this venue.

Linkages with Other Programs:

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). The EHDI Program is located in the same service unit as the Special Child Health Services Registry, Family Centered Care Services (with responsibility for the county Case Management Units - CMUs), and the Part C Early Intervention (EI) program. This organizational structure has facilitated data sharing and collaborative efforts. As noted previously, an agreement with EI allows the EHDI program to obtain information about enrollment on children with hearing loss.

Relationships with other Divisions of the DHSS include those with the NJIIS program in the Division of Epidemiology, Environmental, and Occupational Health. NJIIS staff has been enthusiastic about the inclusion of hearing information in their system. As noted under progress on Objective 2.2, the EHDI program has recently established a linkage with the Medicaid managed care program in the Department of Human Services. The Medicaid managed care providers previously had access to a section in the NJIIS system to upload and download immunization data for their members. This interface was expanded to allow the managed care providers to obtain inpatient screening results and outpatient follow-up status for their members, so that these organizations can partner with the EHDI program in ensuring timely and appropriate follow-up for their infant members.

Another strong relationship is with the Bureau of Vital Statistics and Registration (BVRS). The BVRS ensures that Electronic Birth Certificate (EBC) data is provided to the EHDI

Program, and is including the EHDI staff in the planning process for development of an updated web-based EBC system.

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, membership on the Deaf and Hard of Hearing Advisory Council, collaborating on revisions to the EHDI 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 that are responsible for programs for children with hearing loss.