

Project Narrative

List of Acronyms

AAP: American Academy of Pediatrics
ASL: American Sign Language
CDC: Centers for Disease Control and Prevention
CMU: Case Management Unit
D/HH: Deaf/Hard of Hearing
DMP: Deaf Mentor Program
DOH: Department of Health
EAC: EHDI Advisory Committee
EHDI: Early Hearing Detection and Intervention
EI: Early Intervention
EIM: Early Identification and Monitoring
FCC: Family Centered Care
FHS: Family Health Services
HRSA: Health Resources and Services Administration
HSFS: Hearing Screening and Follow-up Survey
NJEIS: New Jersey Early Intervention System
NJIIS: New Jersey Immunization Information System
NS&GS: Newborn Screening and Genetic Services
PCP: Primary Care Provider
REIC: Regional Early Intervention Collaborative
RFA: Request for Applications
SCHEIS: Special Child Health and Early Intervention Services
SCHS: Special Child Health Services
SPAN: Statewide Parent Advocacy Network
WIC: Women, Infants and Children (supplemental nutrition program)

Introduction:

Significant hearing loss is one of the most common health conditions present at birth, with national reports of hearing loss identified through newborn hearing screening of 1.7 per 1,000 screened infants¹. In New Jersey, with just under 100,000 annual occurrent live births, an estimated 150 babies are born each year with a permanent hearing loss. Undetected hearing loss impedes speech and language development and may cause cognitive development delays; however, these effects can be minimized or avoided through early hearing loss detection and intervention.

The New Jersey Department of Health (DOH) has a strong infrastructure to support newborn hearing screening. New Jersey has had legislation requiring universal newborn hearing screening and follow-up in place since January 2002. The New Jersey Early Hearing Detection and Intervention (EHDI) program, housed within the New Jersey Department of Health, regularly modifies administrative rules that provide specific and enforceable criteria for birthing hospitals/centers, physicians, and audiologists to ensure provision of newborn hearing screening and follow-up. Initial newborn hearing screening in New Jersey is very successful, with 99.94% of all babies undergoing an initial hearing screening by one month of age. Achieving the national EHDI goals of completing diagnostic audiologic testing by three months of age and enrollment

¹ <https://www.cdc.gov/ncbddd/hearingloss/data.html>

in Early Intervention (EI) by six months, although improved, continues to be an area of needed interventions. Critical elements to achieving these improvements include increasing health professionals' engagement in and knowledge of the EHDI system and improving family engagement and partnership with the EHDI program, as well as identifying and addressing cultural and ethnic disparities that may impact New Jersey's success at reaching these goals. The purpose of the proposed Health Resources and Services Administration (HRSA) grant is to maintain New Jersey's successful initial hearing screening rates and to continue to improve rates of timely diagnosis of hearing loss in one or both ears; referral to and enrollment in Early Intervention (EI) services. Funding will also be provided through subgrants to several New Jersey based agencies that can provide statewide, family-based support to families of children who are Deaf/Hard of Hearing (D/HH) and work to improve family engagement and partnership with the EHDI program.

Needs Assessment:

Target population: New Jersey, although geographically small, is according to United States Census data, the most densely populated State with 1,195 persons per square mile². New Jersey has almost 9 million residents and is the eleventh most populous State, with 2.7 percent of the national population². Hospitals with maternity services and audiology facilities are concentrated more heavily in the northeastern section of the state, consistent with population density and the locations of large cities.

New Jersey currently has about 100,000 infants delivered in the state each year. Currently there are 49 hospitals providing maternity services with annual birth rates at these facilities ranging widely from around 250 births per year to about 6000 birth per year. In addition, New Jersey now has two birthing centers together delivering about 150 infants per year. Home births are very uncommon, representing about 150 (0.15%) of New Jersey births annually.

New Jersey is a racially, ethnically and culturally diverse state. Census data estimates from 2010 reported 54.9% of the population was White, Non-Hispanic, 20.6% were Hispanic, 15% were Black Non-Hispanic, and 10.0% were Asian³. The census data on language spoken in New Jersey households for the years 2009 to 2013 (released October 2015) reveal that 30% of the population speaks a language other than English at home. Of these individuals, 41.2% spoke English less than "very well"⁴. The most common primary languages spoken at homes other than English were Spanish (15.3% of speakers), Chinese (1.3%), Portuguese (1.0%), Tagalog (0.98%), Italian (0.95%), Korean (0.8%), Polish (0.8%)⁴. According to Kids Count data, the number of children under 19 years of age without health insurance has declined from 9.2% in 2010 to 3.7% in 2015, where it has remained stable through 2017; this is below the national average of 5% for 2017⁵.

The 2017 Centers for Disease Control and Prevention (CDC) Hearing Screening and Follow-up Survey (HSFS) data (Table 1 below) highlights where the New Jersey EHDI program has succeeded in meeting national EHDI goals and where additional improvements are still necessary. The implementation of screening by one month of age continues to be successful, however of those babies that did not pass their final re-screening only one-third completed their diagnostic testing by 3 months of age. Although this statistic has remained stable over the past

² <https://www.census.gov/quickfacts/NJ>

³ <https://www.census.gov/quickfacts/NJ>

⁴ <https://www.census.gov/data/tables/2013/demo/2009-2013-lang-tables.html>

three years, this timely referral to and completion of diagnostic audiologic evaluation remains an area needing attention. New Jersey EHDI will continue to make strides to in improving this rate by at least 10% from current baseline during the upcoming project period. Of children with a diagnosed hearing loss, three quarters do get enrolled in Early Intervention (EI) services, but timely enrollment also remains an area needing improvement.

Table 1: CDC HSFS Trends in New Jersey
*Italics indicate grant Objective Measures**

	2015 Births	2016 Births	2017 Births	Project Goal
Number of live births	100,842	100,388	98,950	
Number of babies screened	100,052	99,788	98,312	
<i>Number/Percent of babies screened by 1 month of age (including passed and not passed)</i>	98,119 97%	97,881 98%	96,598 98%	98%: Maintain screening rate
Percent screened (excluding infant died/parents declined)	99%	99%	99%	
Number of babies not passing inpatient screen and did not receive outpatient rescreen	276	252	262	
Number of babies not passing final (inpatient or outpatient) documented screen	758	717	707	
Number/percent of babies that did not pass final screening with diagnostic exam completed (including cases of normal hearing and hearing loss, any age)	397 52%	388 54%	358 51%	
<i>Number/Percent of babies that did not pass final screening with diagnostic exam completed by 3 months of age (including cases of normal hearing and hearing loss, before 3 months of age)</i>	270 36%	241 34%	238 34%	37%: Increase by 10% from baseline over duration of project period
Number/percent of babies with diagnostic exams completed by 3 months of age (of those with documented diagnostic exams)	270 68%	241 62%	238 67%	
Number of babies that did not pass final screening diagnosed with permanent hearing loss	115	140	126	

Number/percent of babies with diagnosed hearing loss referred for Early Intervention services by 6 months of age	81 70%	75 54%	73 58%	
Number/percent of babies with diagnosed hearing loss enrolled in Early Intervention Services	85 74%	101 72%	99 79%	
<i>Number/percent of babies with diagnosed hearing loss enrolled in Early Intervention services by 6 months of age (of those enrolled)</i>	54 47%	59 42%	63 50%	58%: Increase by 15% from baseline over duration of project period

Barriers: One barrier to timely diagnosis after a positive screening can be access to follow-up hearing re-screening and pediatric audiology services. Just under half (21) of the hospitals with maternity services have an in-house audiology department, and only 15 of those offer comprehensive diagnostic audiologic services appropriate for young infants. Ensuring parents, hospital staff, and physicians know where they can receive follow-up services is essential to obtaining both timely outpatient rescreening and audiologic diagnosis. The New Jersey EHDI program has an online resource, the Pediatric Hearing Health Care Directory’ New Jersey (www.hearinghelp4kids.nj.gov) to assist families in finding services throughout New Jersey and its border states. The New Jersey Directory is updated annually by EHDI staff.

In 10 birthing hospitals, including several with audiology services, nursery hearing screening staff will conduct one outpatient rescreening prior to referral to an audiologist. Also, most audiology facilities in New Jersey, both hospital-based and non-hospital based, will conduct an outpatient re-screening prior to one month of age, rather than administer a diagnostic exam. Most babies receiving an outpatient rescreen will pass that screening, thus reducing the number of infants requiring referral for a diagnostic audiologic evaluation. For hospitals without in-house audiology services, the availability of nursery-based rescreening services prior to one month of age, reduces the number of families that need to find another location where their child can be tested. With an annual rate of refer on inpatient screening of around 2%, there are about 1,800 children per year in need of outpatient testing. Two-thirds of these babies (around 1,200) receive and pass an outpatient rescreening exam, so are not included in the HSFS numbers noted above as children not passing a *final* screen. New Jersey EHDI has encouraged hospitals and audiologists to complete any outpatient rescreening exams before one month of age in order to allow adequate time for diagnostic testing to be completed under natural sleep conditions no later than three months of age. Delays in scheduling the initial outpatient rescreening can contribute to delays in meeting the goal of completion of diagnostic testing by three months of age. Delays in scheduling may include, but are not limited to, the availability appointments in settings that are in close proximity to the family home, availability of the appropriate rescreening technology and locating an outpatient facility that is within the child’s insurance network.

Another barrier to timely diagnosis is parents and/or primary care providers not recognizing the importance of timely outpatient follow-up testing. The New Jersey EHDI law and administrative rules place the primary responsibility for ensuring initial outpatient follow-up

on the birth hospital. Birthing hospital are mandated to notify the primary care provider (PCP) of the inpatient screening results in writing; notify the parent of the inpatient screening results both in writing and face-to-face; notify the parents of where outpatient follow-up testing is available; and make at least one documented outreach attempt to families in need of additional follow-up by phone call, letter or other communication. Though New Jersey’s birthing centers do not provide onsite hearing screening services, they are required to direct families to outpatient facilities that offer this service. For babies who, despite best efforts, do not have follow-up documented after several weeks, case managers contracted through the current HRSA funding conduct outreach via telephone calls to families and/or PCPs as an additional effort to ensure follow-up.

Another barrier to timely diagnosis may be related to insurance impediments to health care access (e.g., delays in initiating insurance coverage for the child). Some insurance policies allow for the child’s outpatient testing to be billed under the mother’s insurance. However, some audiology practices will not schedule appointments until the child has their own insurance card issued to prevent scenarios where the visit cannot be successfully billed. Even when children are eligible for health care services, families may fail to seek care if there are concerns about the immigration status of other family members.

The first barrier to timely EI referral and enrollment is timely diagnosis of congenital hearing loss. Of children diagnosed with hearing loss in the 2017 HSFS, 18.3% were diagnosed after six months of age, so that the timely EI referral and enrollment goals could not be met. Another barrier to the timely EI enrollment is that in New Jersey, may be related to the requirement for families to pay a cost share for EI services based on family income. There is no charge for families whose income is less than 300% of the Federal Poverty level. Some families may not have the resources to cover their designated cost share or may decline services, particularly if they are not seeing any language delays in their child. Denial of the discovery and acceptance of any type of medical diagnosis may delay a family’s pursuit of EI services. In addition, cultural viewpoints toward the characterization of a child presenting with a hearing loss in terms of a disability rather than a cultural difference may also contribute to delays in accessing EI services.

Some families may not be adequately educated about the benefits of EI services, particularly those with a unilateral or minimal hearing loss. For children identified in the 2017 HSFS survey as diagnosed with hearing loss, the EI enrollment rate at any age was 85% for children with a bilateral hearing loss and only 65% for children with a unilateral hearing loss.

Racial and ethnic disparities in EHDI goals also exist and need additional efforts to eliminate. For the 2017 HSFS data, racial and ethnic breakouts for subgroups with at least 10 cases of hearing loss are noted below. Asian families were most likely to have a diagnostic exam completed and African American families were least likely. Asian and White non-Hispanic families were somewhat less likely to enroll in EI.

	Diagnostic Testing completed (any age)	EI Enrollment (any age)
Total	51%	79%
White, non-Hispanic	54%	75%
White, Hispanic	51%	89%
Black/African-American, non-Hispanic	35%	80%
Asian	68%	77%

In New Jersey, in both 2016 and 2017, overall rates of follow-up testing are lower for infants of United States-born mothers compared to all foreign-born mothers. When mother's race/ethnicity is added into the picture, US-born white, Asian and other mothers have higher follow-up rates compared to the foreign-born counterparts. While Black and Hispanic US-born mothers have lower follow-up rates compared to foreign-born mothers within each racial group. Overall rates of follow-up testing are highest for infants of African and Latin American and Caribbean-born mothers; and lowest amongst US and western European-born mothers. The disparity in follow-up rates for Black, non-Hispanic US born mothers is a more important contributor to overall follow-up rates than a mother's place of birth.

Methodology:

Activities to expand infrastructure for hearing screening for children up to age three will be done through New Jersey EHDI's demonstrated leadership and partnership with key stakeholders, including organizations with the shared goal to improve developmental outcomes of D/HH children in the state.

The New Jersey EHDI program has already demonstrated success and will continue to achieve high rates of newborn hearing screening by 1 month of age (goal 1). The EHDI program has shown improvement in successfully achieving diagnosis by 3 months of age (goal 2) and enrollment in EI by 6 months of age (goal 3). EHDI will continue to utilize those activities that improved goal 2 and 3 rates and work with its partners to formulate other tactics to add to these improvements.

In order to improve timely enrollment to EI, the EHDI Audiologist will be conducting surveys to pediatric audiologists on their knowledge of and use of referral practices to the NJ Early Intervention System. These surveys will be administered both prior to and after NJ EHDI/New Jersey Early Intervention System (NJEIS) Hearing Consultant outreach activities to determine if rates of referral to NJ Early Intervention System has improved.

In the upcoming HRSA funding period, pending approval of the New Jersey Division of Consumer Affairs-Audiology and Speech-Language Pathology Advisory Committee, New Jersey EHDI plans to collaborate with Head Start programs throughout the state on streamlining their federally required initial hearing screening services within 45 days of enrollment to EI to all children enrolled in both Early Head Start and Head Start programs. Collaboration will also include partnering with University based audiology and speech-language pathology graduate programs and clinical audiology facilities throughout New Jersey to establish evidence-based and accessible screening programs for local and county-based Head Start programs. In addition, New Jersey EHDI will provide training to screeners of children in Early Head Start (birth to 3 years) on reporting results using the New Jersey Immunization Information System (NJIIS) EHDI module.

Throughout the funding period, some activities to be carried out toward the grant objectives will be directed by the EHDI Advisory Committee (EAC), the New Jersey EHDI team, proposed grantees, and the Hearing Evaluation Council. The EAC will develop a meeting framework for health care professionals and families of children identified with hearing loss to engage, partner, learn and advise. The EAC will be composed of stakeholders such as health care professionals, representatives from collaborative agencies, and at least 25% of members will be parents or family members of D/HH children and/or D/HH individuals. There will be a minimum of two meetings for the EAC each year. The first EAC meeting will be conducted in April 2020.

The New Jersey EHDI program has experience with convening and facilitating multidisciplinary groups. This existing framework will be used to reconvene meetings with the EAC, requiring far less preparatory time to become effective than if they were newly established. The EHDI program has also already received commitments to participate on the EAC from representatives of the organizations and groups required by the funding opportunity announcement. The Social Worker 2 Psych/Deaf Language Specialist will facilitate the work of this group.

The New Jersey EHDI program has had an advisory board - the Hearing Evaluation Council, in place since 2005, whose membership is specifically designated in New Jersey's hearing screening legislation:

“The commissioner shall establish a Hearing Evaluation Council to provide on-going advice to the department on implementation of this act. The council shall be composed of not less than seven persons appointed by the commissioner who 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.”

The EHDI program will seek to ensure a mechanism of communication and partnership between the Hearing Evaluation Council and the EAC.

Activities to educate health care providers on the 1-3-6 guidelines (screen by 1 month of age, diagnosis by 3 months of age, EI enrollment by 6 months of age) and on improving family engagement and cultural competency, will occur throughout the four-year funding cycle and will impact all grant objectives. Educational activities will be conducted by the DOH EHDI team, as well as by the New Jersey American Academy of Pediatrics (AAP) EHDI Chapter Champion and by subgrantees. These activities will include presentations at conferences, webinars and meetings, as well as individual education to primary care providers and audiologists.

New Jersey continues to be one of the most diverse states in terms of race, ethnicity, and culture (see page 2, Needs Assessment). The EHDI team focuses its efforts on addressing the wide population ranges of New Jersey to ensure that hearing screenings, follow-up, and provision of written educational information are accessible for all families and their children. For example, on the New Jersey DOH newborn hearing screening website, brochures on the importance of newborn hearing screening (Can My Baby Hear?) and what to do when a baby needs another hearing test (My Baby Needs Another Hearing Test) are offered in the six most commonly used languages in New Jersey. Activities to continue serving New Jersey's diverse populations will be constructed and ready for implementation by the end of year 2 (see Attachment 1), including, but not limited to, provision of New Jersey EHDI materials in American Sign Language videos for posting on the EHDI website.

Many of the activities of the funding period will be carried out by one of several organizations that can provide statewide family-based services for families of children with hearing loss. Funding to subgrantees will require submission of applications by these organizations through a Request for Applications (RFA) process which ensures fairness of funding availability to all qualified organizations and allows for transparency of allocation of Federal funds. The RFA process will begin in early 2020, with the intent to select awardees no later than April 1, 2020 and have written agreements with the agencies in place no later than 90 days after the beginning of the funding period. The following organizations are potential

subgrantees that have expressed an interest in working on the grant objectives with the EHDI program. Letters of Agreement are in Attachment 4.

Each of the New Jersey's 21 counties has a Special Child Health Services (SCHS) Case Management Unit (CMU) jointly funded from Title V funding and the county freeholders. The SCHS Case Managers, with parental consent, work with families of children with special healthcare needs and with the child's physician to evaluate an affected child's strengths and needs and develop an individual service plan for the child and family. The medical, educational, developmental, social and economic needs of the child and family are targeted. Since 2009, the EHDI program has provided subgrant funds through the current HRSA EHDI grant to one of these CMUs that is housed within the Mercer County Special Services School District. That unit is responsible for EHDI services for children statewide, with funding provided to just one county in order to consolidate expertise and ease program administration. Through this subgrant, the CMU staff, including one bilingual (English/Spanish) case manager, conduct outreach to families of children that need follow-up after initial hearing screening, including outreach to families of children that did not pass on outpatient rescreening. The case managers provide a variety of support to these families including assisting with enrolling the child in insurance, educating families about the need for additional follow-up and assisting families with other potential barriers to follow-up such as lack of transportation. The case managers have participated quality improvement projects with EHDI staff. See Attachment 4 for current contractual agreement.

Family Link is one of four Regional Early Intervention Collaboratives (REICs) in New Jersey that provide local level leadership in planning and coordinating the New Jersey Early Intervention System (NJEIS). The REICs facilitate access and availability of effective EI services through outreach and collaboration, are responsible for regional system point of entry for referral to the NJEIS, and assist the DOH with data collection, child find/public awareness, family support and personnel development. The REICs are committed to providing a family-centered, family-driven, community and culturally-sensitive system of early intervention services and supports.

Family Link is a current recipient of HRSA EHDI subgrant funds which support the EHDI Hearing Consultant program. The REIC has hired two-part time consultants. One is a speech-language pathologist and the other is a teacher of the deaf and both have extensive experience in working with infants and young children with hearing loss. The consultants make an initial telephone contact with newly diagnosed families who are interested in this service and also participate via videoconferencing in the Family Information Meeting. They have provided services to 130-150 families annually since the program began in July 2012. The goal is to provide families with non-biased information about communication options, to discuss services available through EI, and to provide additional resources to parents. As with the case management subgrant, though the REIC generally provides services to just one of four regions in New Jersey, for this project they provide services statewide in order to consolidate expertise and administrative functions. See Attachment 4 for current contractual agreement. In collaboration with FamilyLink, the Research Scientist 1 will oversee the data system to ensure that there continues to be a data sharing agreement between proposed grantee FamilyLink and New Jersey EHDI.

The Statewide Parent Advocacy Network (SPAN) is New Jersey's federally-designated Family-to-Family Health Information Center and Family Voices State Affiliate Organization. Also under the SPAN umbrella is the New Jersey Statewide Parent to Parent program which

matches a network of trained parents of children with special health care needs to other parents to offer emotional support and information, act as a resource to families, and offer assistance in learning the necessary skills to help parents face the challenges of raising their child.

Under previous HRSA funding, the EHDI program has provided subgrants to SPAN to assist them in recruiting and training additional support parents from families with children with hearing loss. Under current HRSA funding, the EHDI program has provided subgrants to SPAN to assist them in continuing the New Jersey Deaf Mentor Program (DMP). The New Jersey DMP's wide ranging support includes American Sign Language (ASL) Deaf Mentors (who teach ASL to families), Snapshots Deaf Mentors (D/HH adult consumers who serve as role models), Parent to Parent support services, and community events. These services are currently being offered to 22 families with inquiries being made on a weekly basis. Providing this variety of services meets the vastly different needs of families with a child with hearing loss. The general feedback from families, organizations, professionals and the Deaf Community has been overwhelmingly positive. Testimonials and comments from the feedback surveys regarding the training, programs and kick off events were almost exclusively positive, even with the limited time the program has been established. The DMP team shared a passion and vision for this project and each brought their own experiences to understanding the needs of a Deaf Mentor Program in New Jersey. Having a parent of two D/HH children, and a D/HH adult working collaboratively helped immensely in ensuring that the diverse needs of the hearing loss community were being met.

In an effort to contribute toward continuous quality improvement (QI), strategies to monitor and assess program improvements in New Jersey EHDI will occur throughout the four-year funding cycle. Strategies will focus on improvement in the following areas: loss to follow up/documentation and family engagement/family support.

Loss to follow up/documentation The New Jersey EHDI program plans to continue to work collaboratively with birth hospitals and birthing centers to identify children in need of, and overdue for, outpatient follow-up and to verify that reminder contacts to families have been completed. Reports will continue to be sent monthly to facilities to verify children still in need of follow-up testing. New Jersey EHDI also has a pediatrician Fax Back program in place that allows for outreach to the pediatricians identified as the 'future source of care' for infants born in New Jersey. In this innovative program, New Jersey EHDI faxes a brief, check off sheet to pediatricians that asks them to reply via fax on the status of the children in their practice that are considered 'lost to follow-up.' The 'fax back' program has been successful in locating previously missing documentation from audiology practices both in and out of New Jersey; provided New Jersey EHDI with results of hearing screening conducted within pediatrician offices; offered information on possible data entry errors of nursery based hearing screening results and raised awareness of the need for referral for children who need additional testing.

New Jersey EHDI staff and specialty trained Mercer County Special Child Health Services Case Management Unit will continue to provide outreach to pediatricians, audiologists, and families of children in need of rescreening or diagnostic audiologic evaluation. Currently, all referrals to CMU come from the DOH EHDI program and occur after verification of the accuracy of the inpatient hearing screening results. As such, children are often over 1 month of age by the time of the referral. During the proposed funding period, the program will explore and implement a mechanism for hospitals to make direct referrals for this service to improve timeliness of diagnostic testing specifically for diagnosis made before 3 months of age.

New Jersey EHDI has expanded its outreach to our border states in terms of contacting pediatric audiologists who are caring for children who are New Jersey residents, but whose families have elected to pursue services in out of state audiology centers.

In addition, the Pennsylvania and New Jersey EHDI programs, along with the Mercer County SCHS CMU, have begun working together on outreach to New Jersey based families of children born in Pennsylvania hospitals in need of follow-up services.

Family engagement and family support:

The New Jersey EHDI program plans to continue to work collaboratively with proposed grantee FamilyLink Inc. as they reach out to families with D/HH children to encourage EI enrollment, educate families on communication methods/needs/resources/services, and work toward receiving timely referrals from audiologists and/or PCPs to assist families after hearing loss diagnosis.

The New Jersey EHDI Coordinator's title is Social Worker 2 Psych/Deaf Language Specialist. She is a Deaf adult consumer and as a new activity during the proposed funding period she will work with FamilyLink to assist in speaking with families regarding Deaf culture, Deaf awareness, communication methods/needs/resources/services, and answer any questions pertaining to life as a Deaf individual. The New Jersey EHDI Coordinator, who is a licensed social worker in the state of New Jersey and former teacher for Deaf/Hard of Hearing children, possesses background and training in clinical social work which enables her to work with families of D/HH children.

The New Jersey EHDI website (<https://nj.gov/health/fhs/nbs/ehdi/>) continues to evolve by offering consumers and professionals accurate, useful, timely, and comprehensive information that contributes to the accomplishment of 1-3-6 milestones for infants and young children suspected of having or who have been diagnosed with hearing loss. The website has been designed to provide guidance about the EHDI process to specific stakeholder groups including birthing facilities, families, audiologists and healthcare providers. The layout of the website allows for ease of locating information on New Jersey EHDI's law and regulations; Pediatric Hearing Health Care Directory; newborn hearing screening and follow-up brochures in the 6 most common languages used in NJ; and links to the various forms used by health care providers in meeting their regulatory reporting requirements. In addition, the main page of the New Jersey EHDI website features a video from the British Columbia Early Hearing Program ('Nice to Meet You') that introduces viewers to a diverse group of Deaf and hard of hearing students and young adults who share their first-hand experiences and wisdom as they answer questions on what it is like to grow up with hearing differences. Future website features will be designed through collaboration with New Jersey's parent advocacy agencies; the New Jersey Early Intervention System and the New Jersey Division of the Deaf and Hard of Hearing to include information on parent support, advocacy and engagement services that will serve to enhance the experiences faced throughout a child's hearing loss journey from diagnosis to early intervention to transition to early education services. In addition, the website will include recordings of educational webinars presented via the New Jersey EHDI Pediatric Hearing Health Care series as well as videos of pertinent EHDI information presented in American Sign Language.

New Jersey EHDI will continue to consult with HRSA-20-051 (Family Leadership in Language and Learning for resources, technical assistance, training, education, QI, and evaluation to ensure a strong infrastructure and capacity for family engagement and family support in the state/territory.

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

Work Plan:

Attachment 1 provides an overview of the activities to be conducted during the four-year funding cycle as well as the goals and objectives and the timelines for the activities. A logic model is also attached to demonstrate the conceptual framework for this funding cycle.

Resolution of Challenges:

Providing subgrantee funding requires a time-consuming administrative process. The EHDI program intends to begin to develop and release the RFAs for the subgrantees in early 2020 in order to be able to allocate subgrantee funds as close as possible to the start of the funding period.

The Deaf Mentor Program may require additional outside funding to support providing Deaf mentors with additional training from their training program, Ski Hi. SPAN will be responsible to seek outside funding supports where needed.

The improvement goals for timely diagnosis and EI referral and enrollment that are specified in the funding opportunity announcement are optimistic, since the most easily remedied barriers to timely follow-up have already been identified and addressed by previous program work. However, planned activities to decrease the time lag in referral may be able to make a measurable difference in the overall rate. Some barriers to timely diagnosis are out of the control of the EHDI program. For example, babies that deliver very prematurely may neither be stable for screening by three months of age nor able to be diagnosed by three months. This can similarly affect EI enrollment timelines. There is little that the EHDI program can do to decrease the rate of families that decline EI services due to the family cost share. The program will closely monitor progress on the goals and work to identify and direct activities at areas where progress is most likely to be achieved.

Evolution and Technical Support Capacity:

The EHDI program has a strong data infrastructure to be able to evaluate progress toward the grant objectives. Most data required to assess progress on objectives are captured electronically and updated frequently. Tracking of process measures will be captured by mechanisms such as logs for meeting attendance and completion dates of documents to be developed. The Work Plan (Attachment 1) identifies these measurements. Inpatient results are captured in the state's electronic birth certificate system, the Vital Information Platform VIP and weekly extract files are incorporated in the EHDI data system. Outpatient follow-up exams are reported via the immunization registry, the NJIIS, and that data is also imported weekly into the EHDI data system. This allows for excellent tracking of timely diagnostic follow-up. Because the EHDI program is organizationally situated within the same service unit as EI, a data sharing relationship has been developed. Evaluation activities will be carried out by the EHDI Research Scientist who has extensive experience with data analysis and evaluation activities and the Data Analyst Trainee. To disseminate EHDI program information, including grant activities and

results, the EHDI program routinely uses webinars for communication. The EHDI staff have arranged numerous presentations to hospital EHDI screeners and coordinators, audiologists, case managers and EI providers. The program intends to continue utilizing this format to share results during the proposed funding cycle. The New Jersey EHDI staff routinely share successes via the annual EHDI conference. In 2019, EHDI staff presented a poster exploring follow-up rates in infant born to mothers who were US born versus foreign born. In 2018 EHDI presented two posters, one regarding cytomegalovirus screening at New Jersey hospitals and the other about an activity to provide EHDI education to case managers.

Organizational Information:

The mission of the New Jersey DOH is to improve health through leadership and innovation with the specific goals of Family Health Services (FHS) focused on promoting and protecting the health of mothers, children, adolescents, and at-risk populations as well as to reduce disparities in health outcomes by ensuring access to quality comprehensive care. FHS consists of four service units: Maternal and Child Health Services; the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) Services; Community Health and Wellness Services; and Special Child Health and Early Intervention Services (SCHEIS); as well as the Office of Primary Care & Rural Health and Fiscal & Grants Management. All units within FHS work to improve the health, safety, and well-being of families and communities in New Jersey and support the goals of the Maternal and Child Health Block Grant. SCHEIS, the Title V program for children with special health care needs, is comprised of four programs: Early Identification and Monitoring (EIM), Newborn Screening and Genetic Services (NS&GS), Family Centered Care (FCC) Services, and the New Jersey Early Intervention System (NJEIS). NS&GS is responsible for tracking all newborns with abnormal bloodspot screens, ensuring they are rescreened, and that they are in treatment if diagnosed with a disorder and for maintaining the EHDI program and the Critical Congenital Heart Disease screening program. EIM is responsible for maintaining the Birth Defects and Autism Registry. FCC and NJEIS offer comprehensive management of multiple programs and services that enhance the health, safety and well-being of families and communities in New Jersey. FCC serves children of all ages who present with complex medical conditions. FCC is responsible for the 21 county-based case management units that are jointly funded by SCHS and county freeholders and for the HRSA Ryan White program. In July 1993, NJEIS was designated the lead agency for Part C of the Individuals with Disabilities Education Act when these services were transferred to DOH from the New Jersey Department of Education. NJEIS serves children up to age three who have developmental delays or disabilities.

New Jersey historically has had a strong infrastructure to support newborn hearing services, with staff responsible for ensuring testing, follow-up, diagnosis, and EI all located together both physically in the same building and floor, as well as organizationally, facilitating the cooperation and collaboration necessary for a successful EHDI program. Timely hearing follow-up testing was included in the State Performance Measures in the Maternal Child Health Block Grant, attesting to the support for EHDI services within the Title V program. The collaboration with other units in FHS and integration with other programs such as FCC and NJEIS can be beneficial in sustainability of activities in the absence of HRSA funding.

The New Jersey EHDI program has received HRSA EHDI funding since 2002 and CDC EHDI funding since 2000 with successful implementation of projects and progress on goals. See Attachment 6 for the current HRSA funding period summary progress report.

The core EHDI project staff is a mix of participants with an array of experience (see job descriptions and biographic sketches, Attachments 2 and 3), each of them contributing their knowledge and expertise to build what is the NJ EHDI empire.

Ariel Meltzer is the Social Worker 2 Psych/Deaf Language Specialist for the EHDI program and joined DOH and the EHDI program in June of 2019. She is responsible for convening the EAC. She is responsible for managing and overseeing the grantees as well as monitoring the DMP. She assists the EHDI Audiologist with newborn screening follow-up. She is a licensed social worker and a member of the National Association of Social Workers.

Nancy Schneider is the Research Scientist 2/Audiologist for the EHDI Program since joining the DOH in 2003. Her pediatric clinical audiology experience was obtained as the Senior Clinical Audiologist at a university teaching hospital, including co-design of their nursery-based hearing screening program. She was an adjunct faculty instructor in an American Sign Language Studies program and has extensive experience with increasing engagement and knowledge of audiologists on all aspects of pediatric audiology. Ms. Schneider also serves as Chairman of the Audiology and Speech-Language Pathology Advisory Committee at the New Jersey Division of Consumer Affairs

Claudia Pollet, a former primary care physician with an MS in Public Health, is the Program Manager of the Newborn Screening Program at NJ DOH. She supervises the EHDI Coordinator and the EHDI Audiologist. Because of her background as a primary care physician, she will be involved in educating primary care providers throughout the state on early hearing screening and the importance of prompt follow up of babies with abnormal screening, so that permanent hearing loss can be detected, and early intervention enrollment can occur in a timely manner. She will also inform them of services available to New Jersey babies and toddlers with permanent hearing loss and the support services available to their parents.

Nicole Dennis is the Data Analyst Trainee for the EHDI program and joined DOH and the EHDI program November 2018. She ensures providers report timely and appropriate newborn hearing screening and follow-up services, through monthly and weekly reconciliation reports. She also trains and creates new user accounts for NJIIS EHDI and will assist with evaluation activities.

Kathryn Aveni is the Research Scientist 1 and serves as the data systems coordinator for SCHEIS. She worked exclusively with the EHDI program from 2002 through 2017 and now works with all SCHEIS data systems and will insure data sharing activities with EI as well as ensuring children documented as D/HH are appropriately followed in the birth defects registry and FCC system.

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