Early Hearing Detection and Intervention Program
Project Narrative
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INTRODUCTION

New York State Department of Health (NYSDOH) is strongly committed to working towards the Early Hearing Detection and Intervention (EHDI) 1-3-6 and Healthy People 2020 goal to "increase the proportion of newborns who are screened for hearing loss no later than one month, increase the proportion of newborns who receive diagnostic audiologic evaluation no later than three months for infants who did not pass the newborn hearing screening, and increase the proportion of infants who are enrolled for intervention services no later than six months."[1]

These principles guided the enactment of Public Health Law to institute the newborn hearing screening program for New York State (NYS) and an amendment to the law which required the collection of individual identifiable hearing test results for the purpose of tracking and surveillance.

The goal of the New York Early Hearing Detection and Intervention (NY EHDI) Program is to ensure that the state achieves the 1-3-6 goals of screening by one month of age, diagnosis by three months of age, and early intervention by six months of age.

Early Hearing Detection and Intervention programs include screening, tracking and follow-up, identification and intervention. Universal newborn hearing screening and reporting results to the NY EHDI Information System (NY EHDI-IS) is one component of the NY EHDI Program, which also includes steps for tracking and follow-up of infants who do not pass newborn hearing screening and provisions for referral of infants who require diagnostic audiological evaluation. NYS Public Health Law requires all maternity hospitals and birthing centers to administer newborn hearing screening programs. Under NYS Public Health Law, primary care providers and audiologists must report diagnostic hearing test results to the Department using the statewide NY EHDI-IS. Since the inception of New York's EHDI program, the Child Find component of the NYS Early Intervention Program (EIP) has served as a safety net for infants who did not pass the initial hearing screening and did not receive timely follow-up by the hospital, an audiologist, of the primary care provider after discharge.

The purpose of this grant application is to outline how the NY EHDI Program will fulfill the requirements of the grant with the goal to support comprehensive and coordinated state EHDI systems of care so families with newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing (DHH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI). For the period 2020 – 2024, the NY EHDI Program will:

- Ensure that all newborns are screened by one month of age, diagnosed by three months of age, enrolled in EI by six months of age (1-3-6 recommendations), and reduce loss to follow-up/loss to documentation
- Develop a plan to expand infrastructure for hearing screening for children up to age three

[1] www.healthypeople.gov.

- Establish and maintain partnerships for referral, training, and information sharing with other state organizations and programs
- Convene a state advisory committee meeting, at least once annually
- Develop a plan to address diversity and inclusion in the state EHDI system
- Develop and implement continuous quality improvement to monitor and assess program performance
- Maintain and promote EHDI webpage that is user friendly, allowing families to make important decisions in a timely manner
- Conduct outreach and education to health professionals and service providers
- Actively engage families throughout all aspects of the EHDI Program by conducting outreach, education, facilitation of partnerships, and continued family engagement and family support activities
- Develop plan to improve coordination and care services across early childhood programs
- Implement and update a plan for project sustainability annually.

The methods will be used to achieve the state EHDI 1-3-6 goals include engaging the NY EHDI Advisory Group to provide guidance, continuing quality improvement activities, updating and promoting EHDI webpage, collaborating with family-based programs to facilitate regional meetings and virtual forums, collaborating with the NYS Council on Children and Families to coordinate care, educating and training newborn hearing screening managers, audiologists, pediatric primary care providers, EI Officials, and EI providers about the importance of timely newborn hearing screening, diagnostic, referral, and enrollment in EI services. The grant activities detailed will be described in later section.

The projected outcomes by March 2024 will be expected as follows, which also strive to achieve the objectives of the grant:

- Maintain at least a 95 percent screening rate of infants that completed a newborn hearing screen no later than one month of age.
- Increase by 10 percent from baseline the number of infants that completed a diagnostic audiological evaluation no later than three months of age. Baseline data are from 2017 CDC EHDI Hearing Screening and Follow-up Survey (HSFS) (24.8%).
- Increase by 15 percent from baseline the number of infants identified to be DHH that are enrolled in EI services no later than six months of age. Baseline data are from 2017 CDC EHDI Hearing Screening and Follow-up Survey (HSFS) (53.9%).
- Increase by 20 percent from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age. Baseline data will be collected from year 1.
- Increase by 10 percent from baseline the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age. Baseline data will be collected from year 1.
- Increase by 10 percent from baseline the number of health professionals and service providers trained on key aspects of the EHDI program. Baseline data will be collected from year 1.

NEEDS ASSESSMENT

To understand the needs of infants who have failed to pass a newborn hearing screening and their families, it is important to understand the environment in which they reside and the system of services and care on which they depend. To that end, this needs assessment provides the broader context of the characteristics of New York State's (NYS) population and then describes what is known about infants and their families relating to newborn hearing screening and follow-up after failure to pass the initial screening, as well as the referral process to the NYS Early Intervention Program (NYS EIP). In addition, while newborn hearing screening rates (by one month) have been stable over time, achieving and documenting timely diagnostic audiological evaluation is more challenging. Given that initial screening rates are good, requiring a 2-stage screen prior to discharge should help to improve referral rates and decrease the follow-up burden for birth hospitals and counties. This requires a change in regulation, which has been initiated.

NYS Population Characteristics

Total Population[2]: According to the 2017 American Community Survey estimates, NYS is home to over 19 million people, or six percent of the U.S. population, and is the fourth most populous state in the nation (behind California, Texas, and Florida). Forty-three percent of NYS citizens (over 8 million persons) reside in New York City. Out of the total population, 51% (10.2 million) were females and 49% (9.6 million) were males. The median age was 38.4 years. Approximately 6% of the population was under the age of 5 years, 18% were 5-19 years, 34% were 20-44 years, 27% were 45-64 years, and 15% was 65 years or older.

Diversity[2]: NYS is notable for the great diversity of both its geography and its people. New York's population reflects diverse race and ethnicity and is more diverse than the nation as a whole. NYS has higher percentages of non-Hispanic Black residents, Hispanic residents, and immigrant residents than the U.S. average. According to the American Community Survey conducted by the U.S. Census Bureau, NYS ranks third of all states in the percentage of its residents that are foreign born, with 22.7% of its total population people being foreign born in 2013-2017. The largest group of foreign-born New Yorkers is from Latin America (49%). Asians are the second largest group of immigrants (29%), and Europeans the third (16%). Almost 90% of New York's noncitizen immigrants live in New York City.

Languages[2]: There is great diversity of languages spoken in NYS. According to the 2017 American Community Survey, of the approximately 18.5 million New Yorkers over age 5, 30.6 percent spoke a language other than English at home. And 13.6 percent reported that they were identified as having limited proficiency in English. Spanish is the most common foreign language spoken at home.

Hospitals: NYS has a regionalized system of perinatal care, structured around a series of Regional Perinatal Centers (RPC). All obstetrical hospitals are designated levels of perinatal care

[2] 2017 US Census.

(obstetrical and neonatal) provided at their facility. In NYS, there are 46 Level I perinatal hospitals, 26 Level II, and 34 Level III, lead by 17 RPC hospitals.

Based on individual data reported via the vital records system, for inpatient screens in 2018, 95% of all hospitals utilized the Automated Auditory Brainstem Response (AABR) equipment for initial hearing screening purposes. Of those, 49% have both AABR and Otoacoustic Emissions (OAE) technology available to screen infants. Out of the 123 birthing hospitals, seven (6%) have only OAE screening technology.

Audiologists[3]: According to the NYS Education Department, there are currently 1,547 licensed audiologists in NYS. The NY EHDI Program has contacted all audiologists in the State and identified approximately 280 audiologists who treat infants.

Pediatric Primary Care Physicians: There are approximately 5,278 licensed pediatricians in NYS, and approximately 4,627 licensed family physicians. These physicians serve as the medical home for newborns and their families. Physicians typically serve as the first point of contact for families after discharge from birthing hospitals. Physicians need to access pertinent data about newborns, including newborn blood spot testing, immunization, and newborn hearing screening, in a timely manner to assist in appropriate follow-up.

Family Support Organizations: Hands & Voices of NY was established with the support of the NY EHDI Program in 2012 and has attained 501 (c) 3 status as well as permanent chapter status with the National Hands & Voices. The chair for the group is a parent of a child that is deaf or hard of hearing. The EHDI Program Coordinator has been an active member on the Board of Directors of Hands & Voices of NY from the initial establishment of this organization and provided leadership activities including developing the strategic planning as well as planning local events held for families of children who are deaf or hard of hearing. The group has established a sustainability plan for maintaining the organization into the future. The group has created a bi-monthly newsletter, a website, a Facebook page and has an electronic mailing list of approximately 100 interested readers.

Births[4]: As instructed in the HRSA guidance document to applicants, data included in this section are based on calendar year births in 2017 and will be used as the baseline measurement. In 2017, there were 230,271 occurrent births in NYS. Of those births, over 50.8% were born in NYC and 49.2% were born in the rest of the state. **Target Population:** Of the 230,271 births, 224,630 (97.6%) had a documented hearing screening. Out of the 224,630 screened, 219,718 (97.8%) received their newborn hearing screening before one month of age.[5]

NYS currently requires one inpatient newborn hearing screening be conducted. If the infant passes the initial inpatient hearing screening, there is a "pass" documentation and the screening process ends. Of the infants that were screened initially, 217,488 (96.8%) passed their initial newborn hearing screening. If the infant does not pass their initial newborn hearing screening, they are referred for follow-up and/or diagnostic audiologic evaluation. Of the infants

[3] New York State Education Licensure, 2019.
[4] NYSDOH Annual Report of Vital Statistics, 2017.
[5] CDC Hearing Screening and Follow-up Survey (HSFS), March 2017

screened initially, 7,142 (3.2%) referred their initial newborn hearing screening, 68.9% of whom passed their follow-up screening.

Among the 2,218 infants that did not pass their most recent screening, 43.5% of infants had a documented diagnosis in the NY EHDI-IS. From the infants with documented follow-up, 630 were found to have normal hearing and 334 had a diagnosis of deaf or hard of hearing. In NYS, 550 (57.1% among the Diagnosed) infants met the three-month benchmark.

New York's EIP is administered locally by the state's 57 counties and New York City. The program serves nearly 70,000 children and their families each year. The Division of Family Health oversees the Bureau of Early Intervention (BEI), which administers and supports the NYS EIP and the NY EHDI Program. The New York State Early Intervention System (NYEIS) is the repository for pertinent data related to the provision of early intervention services including: referrals, eligibility, evaluations, individualized family service plan (IFSP) details, services provided, and approved providers.

Children's records in NY EHDI-IS for 2017 were matched to children's records in NYEIS. Among the 334 with documented hearing loss in the NY EHDI-IS, 232 infants were referred to NYSEIP before six months of age. Of those referred, 180 were enrolled for early intervention services (had an initial IFSP) before six months of age.

Based upon the review of data available for infants, the NY EHDI meets the Joint Committee on Infant Hearing (JCIH) benchmarks for many infants, but there are key areas, such as improving documentation for follow-up, where improvement is needed so that all children who do not pass their initial newborn hearing screening will have a diagnostic audiologic evaluation by three months of age and receive the appropriate intervention and referral for intervention services by six months of age.

METHODOLOGY

The purpose of this grant is to support comprehensive and coordinated systems of care for families of newborns, infants and young children who are deaf or hard-of-hearing (DHH) receive appropriate and timely services. Specific focus areas include 1) revisiting initial hearing screening referral rates and requiring a 2-stage inpatient screening; 2) engaging stakeholders to improve developmental outcomes for children who are DHH; 3) engaging, educating, and training health professionals and service providers about the NY EHDI system; 4) strengthening the capacity to provide family support and engage families with children who are DHH; and 5) assessing the current status of coordination across early childhood programs and develop a plan to improve coordination of care and services.

A. Lead efforts to engage and coordinate all NY EHDI stakeholders

1. Improve referral rates following initial inpatient hearing screening

To further the State's ability to meet the EHDI Program 1-3-6 goals, through the regulatory reform process, the NY EHDI Program has initiated proposed regulation changes to require a two-stage inpatient screening process. Specifically, regulations at 10 NYCRR section 69-8.4 will be amended to modify the inpatient newborn hearing screening procedures to require a two-step hearing screening protocol for inpatient well-infants and use of automated auditory brainstem responses (ABR) for infants in the NICU. The requirement will specify the use of otoacoustic emissions (OAEs) or auditory brainstem response (ABR) as appropriate for the initial screening followed by ABR for a secondary screening, in a manner prescribed by the Commissioner. This change is necessary to decrease the number of infants requiring follow-up screening (that is, decrease the refer rate at discharge) and to refine the number of infants that require outpatient follow-up to rule out hearing loss to those infants that are suspected of hearing loss. In addition to addressing suspected hearing loss as early as possible, congenital cytomegalovirus (cCMV) legislation became effective in 2019 and requires cCMV testing within the first month of life for infants suspected of having hearing loss. This requirement heightens the importance of determining which infants are truly suspected of hearing loss as early as possible and prior to discharge from the birthing facility.

2. Expanding infrastructure, including data collection and reporting for infants and toddlers up to age 3

In New York, the EHDI Program is in the Bureau of Early Intervention (BEI), which is also responsible for the statewide Early Intervention Program (EIP) under Part C of the Individuals with Disabilities Education Act. BEI collects data from both EHDI (through EHDI-IS) and the EIP (through its current system, the New York Early Intervention System or NYEIS). In addition, NY will continue efforts to ensure that audiologists serving young children and health care providers are aware of requirements to submit hearing screening and diagnostic findings to EHDI-IS and the availability of such information for purposes of ensuring that children who are deaf or hard-of-hearing receive appropriate follow-up and services.

In addition, BEI is engaged in a Performance Improvement Project (PIP) with Medicaid Managed Care, which is housed in the Department of Health's Office of Health Insurance Programs (statewide Medicaid program). This PIP focuses on young children and includes three areas: 1) blood lead testing; 2) newborn hearing screening; and 3) developmental screening. Participation in this project affords the EHDI team the opportunity to share data with the Medicaid program, educate health care providers in statewide Medicaid Managed Care plans, and evaluate data for quality improvement purposes.

NY supports hearing screening and necessary diagnostic audiological evaluations for children up to age 3 years through its statewide Early Intervention Program as well as through education and training for primary referral sources on the referral processes available to obtain audiological follow-up. Early Intervention guidance memorandum 2003-03, on newborn hearing screening, outlines the process for referring infants who have failed initial two hearing screenings or who have failed an initial inpatient screening and have not received follow-up screening within 75 days of discharge from the birth facility to the Early Intervention Program. As noted above, efforts are under way to decrease the refer rate at discharge. Connecting families of infants with suspected hearing loss with their county EIP will remain an option for follow-up screening and diagnostic audiological evaluation, in addition to referral by primary referral sources and families to audiologists in the community for follow-up.

3. Establish and maintain partnerships for referral, training and information sharing with various state stakeholder organizations and programs

New York will review key partnerships by the end of Year 1 and revise this annually to address gaps in the EHDI system. BEI is engaged through its Early Intervention Coordinating Council in efforts to address workforce capacity to provide early intervention services. Identified gaps in the EHDI system will be raised in quarterly EICC meetings and through the EHDI Advisory Committee to find solutions.

4. Engaging Stakeholders

EHDI Advisory Group

The NY EHDI Program will engage its expanded NY EHDI Advisory Group at least once annually to provide guidance on establishing continuous quality improvement activities; developing a coordinated infrastructure; improving timely screening, diagnosis, and enrollment in early intervention services; and increasing family engagement, leadership and mentorship activities.

The original NY EHDI Advisory Group was established in 2011 as a collaboration of pediatricians, audiologists, parents, the BEI Co-Director, local early intervention officials, and representatives from the Greater New York Hospital Association, the Hospital Association of NYS, the NYS Speech-Hearing-Language Association, and parents of children who are deaf or hard of hearing. Since 2014, the role of this group is to provide guidance and feedback to the NY EHDI Program on past, current, and future initiatives, which include quality improvement activities related to reducing loss to follow-up/documentation for infants who do not receive or

do not pass the initial newborn hearing screening as well as improving family engagement and family support.

In 2014, the NY EHDI Program worked with Family-Based Organizations to expand the advisory membership to ensure that families of children who are DHH and adults who are DHH comprise 25% of the advisory group. The NYSDOH is the State Medicaid and Title V Agency. Department leaders of the Maternal and Child Health Title V Program, the Children with Special Healthcare Needs Program, the Home Visiting Programs, the Supplemental Nutritional Assistance Program for Women, Infant, and Children (WIC), and the Office of Health Insurance Programs (overseeing the State Medicaid Program) were engaged to participate on the advisory group. In addition, members from University Centers for Excellence in Developmental Disabilities (UCEDD) LEND Programs, the NYS Department of Education (overseeing schools for deaf or hard of hearing and the Deaf Infant Program), and the NYS Council on Children and Families (overseeing the Early Head Start Program) were contacted to be members of the committee.

The Department of Health, including the Division of Family Health and BEI, is working with the NYS Council on Children and Families on Child Care Availability Task Force – specifically on a workgroup called the Systems Coordination Workgroup. This Workgroup is charged with looking at ways systems that care for young children can work together to better streamline and be aligned.

5. Addressing diversity and inclusion in the EHDI System

As noted in the Needs Assessment section, New York State is remarkable for the great diversity of both its geography and its people. New York's population reflects diverse race and ethnicity and is more diverse than the nation as a whole. NYS has higher percentages of non-Hispanic Black residents, Hispanic residents, and immigrant residents than the U.S. average. There is great diversity of languages spoken in NYS. According to the 2017 American Community Survey, of the approximately 18.5 million New Yorkers over age 5, 30.6 percent spoke a language other than English at home. And 13.6 percent reported that they were identified as having limited proficiency in English. Spanish is the most common foreign language spoken at home.

Within the Department of Health, BEI resides in the Division of Family Health, which is under the Center for Community Health. In concert with the Department's strategic plan goals, the EHDI Program will continue to ensure that children who are DHH and their families receive timely and culturally appropriate services. In this context, EHDI will re-evaluate its existing strategies, particularly around getting timely information to families of newly identified DHH children, to ensure that accurate and timely information is provided to them in a culturally appropriate way. A plan to address diversity and inclusion in the EHDI system will be developed by the end of Year 2 of the grant. Underserved populations are also a focus of the EICC's Task Force on Work Force Capacity. The Task Force will address vulnerable communities as part of its work. The EHDI team will participate in that Task Force and leverage strategies that are developed by the group and adopted by the Department.

The Department is also exploring the use of telehealth to provide services and support to children and families in the EIP. At the June 2019 EICC meeting, Meredith Berger, Director of Clarke Schools for Hearing and Speech, provided a presentation on telehealth services specifically for children who are DHH and their families, which was well received. BEI plans to continue to explore telehealth and will issue policy and coverage guidelines on the use of this method to deliver certain early intervention services. Similarly, BEI/EHDI will review materials and methods surrounding the EHDI system to align.

6. Monitoring and Assessing Program Performance

Continuous Quality Improvement

With leadership and guidance from the Advisory Group, the NY EHDI Program developed and implemented local learning collaborative initiatives for healthcare professionals and families to achieve the grant objectives to increase the number of infants that have a newborn hearing screening by 1 month, increase the number of infants that complete a diagnostic audiological evaluation by 3 months, and to increase the number of infants identified to be DHH enrolled in EI services no later than 6 months.

The NY EHDI Program has had considerable success with Quality Improvement (QI) initiatives implemented during the previous three-year grant cycle. Using the Institute for Healthcare Improvement (IHI) Model for Improvement and QI methodology, the NY EHDI Program developed two regional Learning Communities to achieve grant objectives. Local teams of professionals worked together to identify the root cause for gaps in systems that were preventing timely initial hearing screening, follow-up, referrals and documentation in NY EHDI-IS. Each individual team identified small changes to implement to improve their system of care and reviewed data to determine if the changes resulted in positive outcomes. These teams used statewide best practices to reduce loss to follow-up and improve documentation. The success of the QI initiative is reflected in the data: in calendar year 2016, 37.5% of infants that referred their initial newborn hearing screening had a diagnostic audiologic evaluation. In 2017, this percentage improved significantly with 43.5% of infants having a diagnostic audiologic evaluation.

The NY EHDI Program will continue to utilize the IHI Model for Improvement with the QI initiatives. The Model for Improvement is compromised of the following components:

1. Aim: What are we trying to accomplish?
2. Measures: How will we know that a change is an improvement?
3. Ideas: What change can we make that will result in improvement?
4. Plan-Do-Study-Act (PDSA) cycles: continuous, rapid-cycle tests of change
5. Spread of successful strategies to other birthing hospitals/providers of care

The NY EHDI Program will use QI as the lens to focus activities specifically geared toward addressing the needs of key stakeholders, which include birthing hospitals, audiologists, pediatric primary care providers, early intervention officials, and families of children who are DHH.

Birthing hospitals represent one of the most critical partners in the success of the EHDI system of care. The birthing hospitals perform the initial newborn hearing screening for over 200,000 newborns each year. Efforts to reduce loss to follow-up begin with the birthing hospitals completing the initial newborn hearing screening before discharge and recording the results through the state's vital record system in a timely and accurate manner. In NYS statute, birthing hospitals are responsible to complete the initial newborn hearing screening and report the results. Additionally, birthing hospitals are responsible to ensure an infant is referred and receives follow-up after a missed or failed newborn hearing screening. The NY EHDI Program will prioritize a training and technical assistance for birthing hospitals that show need for improvement in newborn hearing screening by one month of age and follow-up/diagnostic audiological evaluation rates.

Audiologists and pediatric primary care providers must report newborn hearing screening and follow-up results using the NY EHDI-IS. In NYS, there are 280 audiologists, 5,278 pediatricians, and 4,627 family practitioners who serve pediatric patients. Given the large number of these practitioners, the NY EHDI Program will prioritize QI initiatives to actively engage audiologists and primary care providers to address the specific needs of these professional groups at a scale that can affect change statewide. Audiologists represent providers that report newborn hearing screening follow-up and diagnostic audiological evaluations to NY EHDI-IS. Pediatric primary care providers act as the medical home and likely first point of contact for families upon discharge from the birthing hospital. Both groups must report newborn hearing screening results if performed, but physicians must review the results for all of their newborn patients to ensure that the initial newborn hearing screening occurred, ascertain the results of that initial newborn hearing screening, and refer families for appropriate follow-up as necessary. The NY EHDI Advisory Group and NY EHDI QI team will guide program planning and implementation of activities and review data to measure the impact of changes being tested.

New York's 57 counties and NYC are responsible for local administration of the NYSEIP, including Child Find to locate infants who have been lost to follow-up by the birthing hospitals. Under NYS Statutory Law, birthing hospitals are required to refer any family whose child failed the initial newborn hearing screening and could not be contacted, to the local early intervention official in the child's county of residence. Early intervention programs also provide essential support services for the infants suspected of or identified with permanent hearing loss and their families. The NY EHDI Program, with guidance from the NY EHDI Advisory Group, will review data ad identify strategies to effect change in referral practices and documentation. The NY EHDI staff will prioritize counties or regions in need of improvement and work closely with early intervention staff in these areas to determine barriers to making referrals and locating parents and to identify solutions that can be implemented.

Working with families of infants who are DHH is central to reducing loss to follow-up as well as improving family engagement and family support. As QI activities are implemented to address newborn hearing screening, evaluation, and intervention process and documentation, the NY EHDI Program staff will work with statewide family-based programs to form focus groups on family engagement and family support. The NY EHDI Program will utilize technical

assistance offered through national organizations such as the National Center for Hearing Assessment and Management, the Family Leadership in Language and Learning (FL3) Center, Hands & Voices, the NY EHDI Advisory Group and existing BEI family initiatives to recruit families of infants who are DHH in each region of the state to participate in the focus groups. These focus groups will address access to resources, barriers and gaps in timely and appropriate services, and ideas to improve family engagement and family support.

The NY EHDI Program will participate in federal or regional conference calls or webinars, particularly with other states that may have similar QI activities or demographics. The NY EHDI Program will work with HRSA to identify or support any efforts to share best practices or discuss solutions to challenges in timely and appropriate newborn hearing screening, evaluation, and referral to early intervention services.

7. Develop, Maintain, and Promote EHDI Webpage

The Department of Health has initiated a redesign of its website. BEI is reviewing early intervention website content and will review EHDI information to ensure that family-friendly information is included and easier to navigate. Revisions will be made to make the webpage more user friendly and easily navigable. The NY EHDI Program will engage the NY EHDI Advisory Group and family-support programs to discuss important resources. Contingent on Department approvals, the Department's early hearing detection and intervention information will include links to information about the importance of early hearing detection and intervention.

In conjunction with the Department's website redesign, the EHDI team will develop updated DOH website content specific to early hearing detection and intervention. This facilitate information sharing with audiologists and health care practitioners and assist parents of children who are DHH. Technical assistance content and referral information will be posted. BEI has a Statewide Central Directory of EI providers. This has recently been reorganized to have separate categories for general EI service providers, assistive technology providers, and hearing and speech centers. The Central Directory is filterable by provider type as well. BEI/EHDI will work to further highlight services for children who are DHH and their families in the Statewide Central Directory and ensure that this information is disseminated to EHDI and EI stakeholders. This will support access to specialty providers in the various regions of the State.

8. Sustainability

The NYSDOH is committed to sustaining the NY EHDI program. The State has infrastructure in place through Public Health Law, regulation, and reimbursement systems to ensure newborn hearing screening, follow-up, and early intervention occur in a timely and appropriate manner. The NYSDOH has developed a robust information system that integrates data from the State's vital records system, immunization and lead testing programs to allow the NYSDOH to actively monitor the progress toward EHDI 1-3-6 goals. There are partnerships in place with the Title V MCH Program to ensure that timely follow-up of infants who have failed the initial newborn hearing screening remains a priority for the NYSDOH.

The NY EHDI team has undergone significant change over the past year. The former PI moved to a new position within the Department's Division of Family Health. The Program Coordinator transitioned to a new position in January 2019. EHDI responsibilities were managed by the EHDI Follow-up Coordinator until the end of August 2019 when she moved on to a county position. Recruitment is under way for an EHDI Program Coordinator 1; 27 resumes have been received for this position. BEI will continue the recruitment process and will fill this critical position in the coming weeks. BEI will also begin the recruitment process for a Follow-up Coordinator in the coming weeks. There is currently an EHDI Data Manager who has received a promotional opportunity within the Department of Health; BEI will begin knowledge transfer from the EHDI Data Manager to the larger BEI data team to ensure that EHDI data needs are met and that available EHDI and Part C early intervention data are routinely reviewed and considered together going forward. Following the implementation of an updated EHDI-IS, State resources are utilized to maintain the current EHDI Information System. The current PI directs the Bureau of Early Intervention and provides oversight to the EHDI team as part of that role. Federal funds, if awarded, will continue to be utilized for the position of Program Coordinator and will be leveraged for a Follow-up Coordinator position (Health Program Administrator) as well.

B. Engaging, Educating, and Training Health Professionals and Service Providers

The NY EHDI Program within the Bureau of Early Intervention will continue to engage, educate, and train newborn hearing screening managers, audiologists, pediatric primary care providers, county Early Intervention (EI) Officials, and EI providers about the importance of timely newborn hearing screening, diagnostic, referral, and enrollment in EI services. The NY EHDI Program will guide spread of 1-3-6 recommendations, best practices, and NY EHDI specific information. Due to the size of NYS, spread will likely need to occur in a region by region approach. The NY EHDI Program staff will collaborate with family-based programs to facilitate regional meetings and virtual forums to provide information to NYS birthing hospitals, audiologists, pediatric primary care physicians, and early intervention providers.

The NY EHDI staff will continue to collaborate with the State's University Centers of Excellence in Developmental Disabilities (UCEDDs) to disseminate information regarding identification, evaluation, and diagnosis of hearing disorders, and provision of prompt, quality intervention. The NY EHDI Program partnered with University of Rochester to develop and present a webinar for audiologists to improve follow-up reporting across NYS in Summer 2019. Going forward, the NY EHDI Program will also engage the UCEDDs on the NY EHDI Program's initiatives and will reach out to specialized schools for children who are DHH, including private institutions and/or State schools for the deaf, to further collaboration across the State. The NY EHDI Program will also work with the New York State Academy of Pediatrics (NYSAAP) and the New York State Academy of Family Physicians (NYSFAP) on disseminating information about the EHDI program to their members through newsletters, updates at regional meetings, and by posting materials on their web pages. BEI will explore the ability to provide CMEs and CEUs to bolster participation in EI/EHDI training targeted at physicians and other allied health professionals.

Current BEI training and FICSP initiative have opportunities for on-line training and short video vignettes, a portion of which can be used to support education/training for the EHDI / EI systems in the State and to reach health care providers and allied professionals working with children who are DHH and their families.

C. Strengthening Family Support and Family Engagement

This section discusses BEI/EHDI work toward strengthening capacity to provide family support and engage families with children who are DHH in the EHDI system. This proposed methodology is a combination of State EHDI team-led and contracted EHDI Program family engagement and support activities to engage families in all aspects of EHDI work; develop content and conduct outreach and education, facilitate partnerships among families and health care professionals. Curriculum development to support programs and activities for families of children newly identified as DHH will be a focus area.

The Bureau of Early Intervention's EIP has a longstanding commitment to impart leadership and advocacy skills to parents at the local and State level. The Family Initiative Coordination Services Project (FICSP) consists of three comprehensive Partners Training Sessions with the goal of increasing parent's leadership and advocacy for children with developmental delays and disabilities, including hearing loss. The curriculum includes information on early intervention such as family-centered services and supports; developing family outcomes; every day routines, activities, and places; developing individual leadership goals, advocacy, and policy development; and transition from early intervention to preschool or other supports and services. The training is available to a sample of parents and caregivers of children who are enrolled in the Early Intervention Program. Graduates of the FICSP have gone on to participate in Local Early Intervention Coordinating Councils (LEICCs), the statewide Early Intervention Coordinating Council (EICC), and other venues where they can advocate for their own children as well as all children with developmental delays or disabilities. NYSEIP and NY EHDI staff will collaborate to increase participation by parents and caregivers of children who are DHH.

This opportunity is currently extended to families of children who are DHH and enrolled in the EIP. With a vendor(s) selected through a competitive request for bid process and under the oversight of the EHDI team, New York will pursue focus groups to inform curriculum development for training including parent advocacy and leadership, along with content specific to families of newly identified children who are deaf/hard-of-hearing (DHH)). NY will utilize its Clinical Practice Guidelines on Hearing Loss, which contain fundamental content for this purpose, and infuse updated information where applicable. With this approach as a foundation, NY will replicate its FICSP model for families of infants who are DHH. The goal is that through this parent leadership training opportunity, conducted in all regions of the State, a network of parents to support DHH children and their families will evolve.

Since 1963, University Centers for Excellence in Developmental Disabilities (UCEDDs) have implemented their core functions of providing technical assistance, community education, direct services, data and research, and information dissemination related to developmental

disabilities. UCEDDs leverage their core federal funding authorized under Public Health Law 106-402 (The Developmental Disabilities Assistance and Bill of Rights Act of 2000 or "DD Act") to partner with other federal, state, and local resources to improve developmental disability services. In NYS, there are three UCEDDs that also receive federal Leadership Education in Neurodevelopmental and Related Disabilities (LEND) funding. LEND programs provide long-term, graduate level interdisciplinary training as well as interdisciplinary services and care. The purpose of the

To satisfy the requirement to use 25 percent of funding for family engagement and support activities, the NY EHDI Program will explore a partnership with NYS UCEDD(s) and/or other institutions involved in service delivery or education for DHH children and their families to establish a program that provides family support services to families with DHH children. NY EHDI program staff will oversee and collaborate in work the UCEDD(s) and/or other institutions involved in service delivery or education for DHH children and their families to develop curricula and materials to ensure that professionals and parents are equipped to provide direct family-to-family support services to parents and families with a child newly identified as DHH. Through outreach, the EHDI team and Department's partner(s) will actively engage families with DHH infants to participate in curriculum development leading to identifying support parents who can assume leadership roles within the EHDI community. The Department and its partner(s) will also engage parent volunteers from Hands & Voices of NY, which has an established chapter to provide mentorship opportunities on building a family support organization or program.

Medium to longer range goals stemming from these activities include the development of a group of parents who are trained and can pair with another family – or groups of families coming together – to support one another. Such a group could have monthly calls or video chats with facilitation from the EHDI team on topics relevant to DHH children and families. Training modules will be developed to enhance the State's ability to serve children who are DHH and their families. Additionally, EHDI/BEI will explore, in conjunction with local (county) early intervention partners, potential adult-to-family support services across the State. BEI/EHDI will further discuss options with national technical assistance entities.

The NY EHDI program staff will collaborate and consult with HRSA's Family Leadership in Language and Learning (FL3) Center. The center can provide the Program with valuable information about best practices and models for engaging families as leaders and mentors. NY EHDI Program staff will continue to engage with the National Center for Hearing Assessment and Management (NCHAM), which has hosted webinars about family engagement. The NY EHDI Program will continue to reach out to other state EHDI Programs to learn about successful initiatives.

D. Facilitate Improved Coordination of Care and Services

The NY EHDI staff worked to establish collaborative relationships with early childhood providers in the community. During the first year of the grant, the NY EHDI Program will assess the status of coordination across early childhood programs. The NYSDOH BEI is responsible for

the State administration of the NY EHDI Program and the NYSEIP. NY EHDI Program staff will collaborate with colleagues in BEI and external partners to develop a plan to improve coordination and care services of children who are DHH.

The NY EHDI Program will also work with the NYS Council on Children and Families to align services, including hearing screening and follow-up, for young children. The NYS Council on Children and Families has received a Preschool Development Birth through Five Grant and is working with BEI and others to streamline and align services for children in NY from birth through age 5. Discussions include identification of available programs to serve young children and their families, data sharing and other methods to ensure family-friendly services exist across the State.

BEI/EHDI is also collaborating with NY's Office of Health Insurance Programs (Medicaid program) on two projects – the Connections project, which is part of the State's First 1,000 Days on Medicaid initiative. Connections is a pilot project to improve developmental screening involving several pediatric medical practices and health insurers in a single county in the State. EHDI is also participating in a Performance Improvement Project with Medicaid Managed Care plans that includes early hearing detection and intervention quality improvement. These efforts are part of a larger initiative toward Kindergarten readiness for all children in the State. NY will use data from EHDI, BEI, and other sources as appropriate to evaluate changes in coordination of services by the end of Year 3.

The Annual Conference

At least one NY EHDI program staff and one family leader will participate in the annual Early Hearing Detection and Intervention (EHDI) meeting, networking with parents, stakeholders and other states' EHDI program staff, and learning from peers and professionals to bring back new ideas for achieving the EHDI 1-3-6 goals.

WORK PLAN

Staff resources will be dedicated to implementing, coordinating, and sustaining the project's efforts to support comprehensive and coordinated systems of care so families with infants who are DHH receive appropriate and timely services that include newborn hearing screening, diagnosis, and intervention services. The core NY EHDI team will consist of the EHDI coordinator, a follow-up coordinator, and a data coordinator. The EHDI Coordinator will take a leadership role in developing, administering, and implementing all aspects of the proposed project. The EHDI Follow-up Coordinator will work with EHDI Coordinator to reduce loss to follow-up and engaging families and professionals in these efforts. The BEI/EHDI Data Coordinator will link the project back to the NY EHDI information system. In addition, Administrative Assistance will be partially funded to provide support to personnel and fiscal activities.

Objective 1: By March 31, 2024, maintained at least a 95 percent screening rate of infants that completed a newborn hearing screen no later than one month of age.

Based on baseline individual-level data reported by birthing hospitals, approximately 95.4% of infants (219,718) received a newborn hearing screening before one month of age.

In NYS, there are 123 birthing hospitals that conduct newborn hearing screening and follow-up. During the first month of the grant period, the NY EHDI Program will analyze EHDI 1-3-6 data for newborn hearing screening by one month, diagnosis by three months, and referral and enrollment to early intervention by six months for the state and at the birthing hospital level. Based on the data, the NY EHDI Program will identify regions with low reporting and hospitals that fail to meet the one-month benchmark. Through targeted outreach and engagement, program staff will educate birthing hospitals, audiologists, and pediatric primary care providers about the state's information system and reporting requirements for providers conducting hearing tests on newborns.

During the first year of the grant period, the NY EHDI Program will work on implementation of a regulation change to establish procedures for the use of a two-stage inpatient newborn hearing screening protocol at birthing hospitals to align with National Joint Committee on Infant Hearing (JCIH) evidence-based practices and reduce the number of infants requiring follow-up hearing screening post-discharge. Program staff will work to educate birthing hospital staff on the regulation change and reinforce the importance of timely and accurate reporting on the birth certificate.

The NY EHDI Program will also engage Regional Perinatal Centers (RPCs) and New York Hospital Associations to assist with provider education regarding receiving a newborn hearing screening by one month of age.

In the prior grant period, the NY EHDI Program was involved in a statewide Governor's initiative for an infant's First 1,000 Days on Medicaid. The NY EHDI Program will continue to work with the Office of Quality and Patient Safety (OQPS) on their Performance Improvement Project (PIP). Newborn hearing screening and follow-up is one of the three focus areas of the PIP. OQPS is working with Medicaid Managed Care Organizations (MCOs) to develop and implement a process to identify Medicaid and Child Health Plus (CHP) children who are missing newborn hearing screening, diagnostic audiological evaluation, and referral to early intervention services. Medicaid MCOs are evaluating barriers to services and implementing interventions to address gaps in care.

Objective 2: By March 31, 2024, increase by 10 percent from baseline the number of infants that completed a diagnostic audiological evaluation no later than three months of age. Baseline data are based upon based upon calendar year 2017 birth data reported to the CDC in the HSFS.

Regulatory changes will be pursued to improve newborn hearing screening referral rates at hospital discharge, as noted above. NY EHDI will continue to use data to work with stakeholders to effectuate further improvements in follow-up rates.

Based on individual-level data reported for calendar year 2017, approximately 3% of infants fail to pass their initial newborn hearing screening annually, and among those infants

56.5% (1,254) did not have documented follow-up results reported to the NY EHDI-IS. Of the infants that did not pass the newborn hearing screening, 24.8% received a diagnosis by three months of age. The EHDI Coordinator, the EHDI Data Coordinator, and the EHDI Follow-up Coordinator will examine baseline data statewide and at the facility level. Staff will analyze loss to follow-up rates for infants who did not pass or did not receive a newborn hearing screening, follow-up screening, diagnostic audiological evaluations, and early intervention services. Staff will also analyze rates of infants that receive a diagnostic audiological evaluation by three months of age. A report will be shared with the NY EHDI team, NYSDOH leadership, and statewide family support programs. These data will be generated monthly and will be utilized throughout the grant period to evaluate the impact of implemented changes.

In NYS, there are approximately 280 practicing audiologists who treat infants. The NY EHDI Program will communicate to practicing audiologists about the importance of newborn hearing screening and timely diagnosis. Program staff will provide technical assistance regarding the state's information system and their requirement to report newborn hearing screening and diagnosis results to the Department. Staff will analyze NY EHDI-IS data for completeness and accuracy of reporting diagnostic results. Data analysis staff will generate reports by region to identify reporting gaps. Audiology practices with deficient reporting will be identified in each region to assess their process of reporting and use the IHI Model for Improvement to make small tests of change. Audiology practices will be surveyed to identify specific barriers and challenges seen in the community regarding follow-up as well as barriers to documenting follow-up and/or diagnostic audiological evaluation results into the NY EHDI-IS.

In NYS, there are approximately 5,278 licensed pediatricians and approximately 4,627 licensed family physicians working, and under State Statute and Regulations, if they perform follow-up screening in their offices on newborns, they are required to report the results to the NY EHDI-IS. The Department has established a strong working relationship with the New York State American Academy of Pediatrics (NYSAAP) and the New York State Academy of Family Physicians (NYSAFP). NYSAAP and NYSAFP will be engaged to expand upon current education initiatives for physicians who serve infants. The NY EHDI Program will develop webinars for each region of the state, which will include the importance of the medical home in the EHDI Program and both state and regional data to educate members about progress towards the EHDI 1-3-6 goals. NY EHDI Program staff will attend at least one scheduled NYSAAP and NYSAFP meeting each year with members to disseminate information about the requirement to report newborn hearing screening results and provide technical assistance on reporting the information.

The Bureau of Early Intervention (BEI), which includes the NY EHDI Program, will also initiate work toward becoming a provider of Continuing Education Units (CEUs) and Continuing Medical Education (CMEs) accreditation for webinars and educational activities.

Objective 3: By March 31, 2024, increase by 15 percent from baseline the number of infants identified to be DHH that are enrolled in EI services no later than six months of age. Baseline data are based upon calendar year 2017 birth data reported to the CDC in the HSFS.

Based on data reported through NY EHDI-IS and a match with NYEIS, there were 334 infants who were diagnosed with confirmed hearing loss in 2017. Of those infants, there were 180 (53.9%) infants found eligible and enrolled for early intervention services (had an initial IFSP) by six months of age. The goal is to increase by 15%, the number of newborns and infants who receive timely early intervention services.

The NY EHDI Program is unique among national EHDI Programs because it is administered by the NYSDOH BEI, which also oversees the statewide EIP. The NY EHDI Program staff are supported by and integrated with the NYSEIP organization. NY EHDI Program staff will continue to participate in bureau-wide meetings. At these meetings, NYSEIP staff and NY EHDI Program staff present information about initiatives and important information affecting the birth to three population and families. The NY EHDI Program staff will also be invited to attend bimonthly NYS EIP calls with the 58 counties and will be invited to present on these calls as well. The NY EHDI Program staff has provided webinars to county EIP staff and will collaborate again to develop a training for State and county EIP staff about the EHDI 1-3-6 goals.

The NY EHDI Program staff will collaborate with the NYS Education Department to request aggregate data for the NYS Deaf Infant Program, which serves children under the age of three who have been diagnosed with hearing loss. The NY EHDI Program staff will also engage the LEND Programs and the Family Support Organizations to identify if there are other organizations or foundations that may be serving infants who have been diagnosed with hearing loss with the goal of better quantifying the number of infants who receive follow-up, even if that follow-up is not delivered through the NYS EIP. As described in Objective 3, the NY EHDI Program staff will continue to support the integration of data across programs that serve young children.

Objective 4: By March 31, 2024, increase by 20 percent from baseline the number of families enrolled in family-to-family support services by no later than six months of age. Baseline data will be collected during year one.

UCEDDs and LEND programs provide long-term, graduate level interdisciplinary training as well as interdisciplinary services and care. The NYSDOH has a strong relationship with the three UCEDDs in NYS. One UCEDD LEND staff sits on the NY EHDI Advisory Group. The NY EHDI Program will explore a partnership with NYS UCEDD(s) and/or a program that serves children who are DHH and their families, to develop materials and provide family support services to families with DHH children.

The UCEDD(s) and/or Program will work in collaboration with the NY EHDI Program to develop curricula and materials for use by parents and family members, audiologists, pediatricians and family practice physicians and to support family-to-family engagement for families with DHH newborns and infants. Through outreach and education, the UCEDD(s) and/or Program will actively engage families with DHH infants to participate in trainings, to become support parents, and to assume leadership roles within the EHDI community. Parent engagement will be included in the process of developing materials. In addition, input from

parent volunteers from Hands & Voices of NY, which has an established chapter to provide mentorship opportunities on building a family support organization or program, will be sought.

The NYSEIP has a longstanding commitment to impart leadership and advocacy skills to parents at the local and State level. The Family Initiative Coordination Services Project (FICSP) consists of three comprehensive Partners Training Sessions with the goal of increasing parent's leadership and advocacy for children with developmental delays and disabilities, including hearing loss. The curriculum includes information on early intervention such as family-centered services and supports; developing family outcomes; every day routines, activities, and places; developing individual leadership goals, advocacy, and policy development; and transition from early intervention to preschool or other supports and services. The training is available to a sample of parents and caregivers of children who are enrolled in the Early Intervention Program. Graduates of the FICSP have gone on to participate in Local Early Intervention Coordinating Councils (LEICCs), the statewide Early Intervention Coordinating Council (EICC), and other venues where they can advocate for their own children as well as all children with developmental delays or disabilities. NYSEIP and NY EHDI staff will collaborate to increase participation by parents and caregivers of children who are DHH.

In addition, the NYSEIP's State Systemic Improvement Plan (SSIP) has focused on improving family outcomes. Each county in the State, the UCEDDS, municipal early intervention officials, providers, and parents, and BEI have worked together on initiatives to support families at the local level. NY EHDI will work toward leveraging county-specific SSIP projects, such as connecting families on social media or facilitating family-centered community activities to support families of children who are DHH participating in the EIP.

Objective 5: Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than nine months of age. Baseline data will be collected during year one.

The NY EHDI Program will explore partnering with the National Technical Institute for the Deaf at the Rochester Institute of Technology and/or schools for the deaf or other agencies/institutions that provide services or are engaged with children who are DHH and their families. EHDI/BEI will also seek technical assistance from national centers such as NCHAM and FL3 to support this effort.

Objective 6: Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program. Baseline data will be collected during year one.

Using the curriculum and information developed under this grant to assist families of newly identified infants who are DHH, EHDI/BEI will provide webinars and training for EHDI and EI providers, with the goal of improving the quality and consistency of information provided to families at the time of identification of hearing loss. Outreach and education will be conducted through a variety of methods including: webinars, regional meetings, presentations at conferences, and communication through the NY EHDI listserv. NY EHDI Program staff will give guidance on the 1-3-6 recommendations and the importance of timely newborn hearing

screening, diagnosis, referral, and enrollment into EI services; NYS statute for performing and reporting newborn hearing screening information; the importance of family engagement; and the statewide and regional performance on key hearing indicators. This information will be combined with updated content regarding audiological and other assessments as well as intervention approaches and educational/communication options for young children who are DHH. At the end of year one of the grant, staff will be able to run a report in the database to collect the baseline number of health professionals and providers trained on the EHDI Program, which will assist with targeting further necessary training opportunities over the course of the grant period.

To increase engagement in education and outreach, the NY EHDI Program will also explore providing CEUs and CMEs for webinars offered to health professionals and service providers.

RESOLUTION OF CHALLENGES

New York State has made a long-term commitment to improve the system of early hearing detection and intervention. The work plan proposed for the project involves six specific, measurable, achievable, relevant, and time-sensitive (SMART) objectives and supporting activities that will engage a host of partners, including birthing hospitals, audiologists, early intervention providers, Early Intervention Officials, a variety of NYS State Agencies, family-based programs, family partners, pediatric primary care providers, and professional medical organizations. The principles detailed in the Model for Improvement serve as the core to these collective goals and activities. These changes will result in sustainable positive change for New York's infants and their families.

Some anticipated challenges include:

- The effect of the low prevalence of hearing loss in the population on engaging and sustaining involvement of pediatric primary care physicians, birthing hospitals, audiologists, and early intervention programs;
- Recruiting and supporting the long-term participation of parents;
- Successfully connecting the different service delivery systems and providers involved in the process from identification to intervention;
- Integrating the information in the data systems; and
- Obtaining the metrics related to family engagement and early childhood care coordination

With the prevalence of permanent hearing loss at approximately one to three in 1,000 newborns, its incidence in an individual pediatric primary care practice is likely to be quite low. The low prevalence of the condition may impact the engagement and sustained involvement of stakeholders due to the lack of perceived urgency and importance relative to other medical and developmental issues. The NY EHDI Program will work to educate stakeholders about the importance of early intervention in cases of congenital hearing loss and the need for involvement in improving timely identification and intervention. The low prevalence may impact the recruitment of all necessary stakeholders.

The pediatric primary care provider is a critical resource to reducing the number of infants lost to follow-up after a failed newborn hearing screening in the hospital. The NY EHDI Program has worked closely with the NYSAAP to educate the pediatric community about the importance of early hearing detection and intervention. The NY EHDI Program will continue to work with NYSAAP Chapter Champions (Dr. Ivan Hand, Dr. Sanjiv Amin, and Dr. Elaine Pereira) to recruit professionals to be involved in the EHDI Program and to participate in quality improvement initiatives. The NY EHDI Program will partner with NYSAAP to attend scheduled meetings to raise awareness with the larger community of pediatricians about the NY EHDI-IS and the EHDI 1-3-6 goals. The NY EHDI Program has benefited from this partnership with pediatric health care providers in an effort to ensure that the program is meeting national goals and achieving a medical home for all DHH infants and young children.

Many families in NYS seek care for their children from family practitioners. While the NY EHDI Program has focused its attention on reaching pediatricians, it recognizes that family practitioners are an equally important group of stakeholders. During this grant period, the program will work to engage these family physicians to educate them on the EHDI 1-3-6 goals and the hearing status information they can obtain through the State's information system. The NY EHDI Program will also partner with the NYSAFP to attend scheduled meetings to raise awareness within the larger community of family physicians about the NY EHDI-IS and the EHDI 1-3-6 goals.

The NY EHDI Program recognizes the importance of involving parents, and the stress parents of newborns who may have permanent hearing loss face. It is challenging to recruit parents and sustain their involvement in statewide efforts over long periods of time. NYSDOH has worked to establish collaborations with Hands & Voices of NY. In addition, the NYS EIP has for many years overseen the Family Initiative Coordination Services Project, which collaborates with parents and promotes parent involvement at all levels of EIP. This leadership-training project helps parents of diverse backgrounds learn more about opportunities for parent involvement within the State's EIP, including issues of hearing loss and deafness. To maintain parent involvement, program staff will work directly with interested parents to determine what resources and support (for example, flexibility in scheduling meetings and calls, stipends, reimbursement for travel and child care, or invitation to present at meetings) could help sustain their involvement.

Successfully connecting the different systems and providers involved in the process from identification to intervention is complex. These systems need to be brought together across NYS. The NY EHDI Program is administered by the NYSDOH BEI. The Department and Bureau have experience in building collaboration among the different health and developmental systems, including local early intervention programs, audiologists, physicians, hospitals and birthing centers. The organizational structure supports the NY EHDI program to integrate systems.

The data systems have been developed to collect the critical information needed to make the information available in real-time and to measure the effect of changes. However, the program is relying on integrating four distinct data systems from the initial newborn hearing screenings, which are collected by two separate vital records processes (NYC and rest of State),

to the follow-up and diagnostic audiological evaluation user-entered into the NY EHDI-IS, to the referral and services provided in the NYSEIP. These data systems do not use one unique patient identifier across the data systems. Therefore, the integration of information is complicated. All required data use agreements are in place to integrate the data systems, and staff within the NYSEIP and NY EHDI have the technical expertise to undertake the steps to integrate the information.

Assessing family-to-family support services and DHH adult-to-family support services through the collection of dated related to enrollment will be a new activity for the NY EHDI Program.

NYSDOH is confident that the resources, personnel, and organizational structure proposed for the project will allow the program to meet and adequately respond to each of these challenges. In addition, the NY EHDI Program will work with the established NY EHDI Advisory Group to ensure timely resolution of emerging issues, problems, and challenges. This team will include a focus on any systemic barriers and will actively engage community leaders and providers.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

To monitor progress and evaluate the extent to which the project is successful in achieving its goals, the NY EHDI Program will evaluate process and outcome measures.

Process Evaluation

The process evaluation will monitor whether the activities were conducted as planned and according to the principles of the Model of Improvement. The process evaluation will address the following questions:

Are the needed resources in place?

- Is there adequate representation of key stakeholder organizations in all project activities? Are the right individuals involved as active partners to effect change?
- Does the Advisory Group include families and DHH individuals? Do they makeup 25% of the membership?
- Has a partnership been established with a UCEDD(s) or other appropriate institution(s)? Is the family support program being developed?

Is the project being implemented as planned?

- Are external partners recruited and actively participating?
- Are families actively participating?
- Are other programs that serve young children engaged and collaborating on integrating data?
- Are reports and data being shared effectively and routinely with internal and external stakeholders?
- Are partners/participants satisfied with the activities performed?

- What unanticipated challenges have been encountered? How have they been addressed?

Has meaningful change occurred at all systems levels as expected?

- Do partnerships result in enhanced outcomes beyond those achievable as individual organizations or stakeholders?
- Do policy and system changes reflect priorities and practices based on meaningful, relevant data and input from key stakeholders?
- Are resources and tools developed acceptable to the populations that are intended to use them?
- Are clinical tools acceptable to providers and feasible for use in practice?
- Do activities result in measurable improvements among target group(s) in knowledge, attitudes, skills, confidence, and other determinants of behavioral/practice change?
- Have provider practice patterns changed to demonstrate improvement related to the specific activities outlined in the workplan?
- To what extent has the project influenced these process measures?

Outcome Evaluation

The outcome evaluation will assess the progress toward achieving a series of outcomes to demonstrate that activities have created positive change. The program will document improvements resulting from the implemented QI process. The outcome evaluation will address the following questions:

- Has the percentage maintained at least a 95 percent in the number of infants who receive a newborn hearing screening by one month of age?
- Has there been an increase by 10 percent from baseline in the number of infants who receive a diagnostic audiological evaluation by three months of age? Baseline data are from calendar year 2017 data reported to the Centers for Disease Control and Prevention (CDC) in March 2019.
- Has there been an increase by 15 percent baseline in the number of infants who are identified to be DHH enrolled in EI services by six months of age? Baseline data are from calendar year 2017 data reported to the Centers for Disease Control and Prevention (CDC) in March 2019.
- Has there been an increase by 20 percent from baseline in the number of families enrolled in family-to-family support services by six months of age? Baseline data will be collected during Year 1.
- Has there been an increase by 10 percent in the number of families enrolled in DHH adult-to-family support services by nine months of age? Baseline data will be collected during Year 1.
- Has there been an increase by 10 percent in the number of health professionals and service providers trained on key aspects of the EHDI Program? Baseline data will be collected during Year 1.

A project evaluation team will implement the project evaluation plan. The quantitative data are collected through the State's vital records systems, the immunization system, the NYS Early Intervention information system, and the NY EHDI-IS and are stored in secure servers. Specific staff involved in the program evaluation and data analysis have been granted access to the data. SAS is the primary analytic software used by analytic staff. Qualitative information about the process evaluation measures will be collected by the EHDI Coordinator, the Data Coordinator, and the family support organization or program and will be evaluated and synthesized into interim and final reports.

Evaluation findings will be summarized and shared with the NY EHDI Advisory Group as well as internal and external stakeholders. Ongoing findings will be utilized to refine the initiative and inform all QI initiatives. In addition, evaluation findings will be disseminated to help sustain partner commitment and funding for initiatives.

ORGANIZATIONAL INFORMATION

NYSDOH's mission is as follows: "Working together and committed to excellence, we protect and promote the health of New Yorkers through prevention, science and the assurance of quality health care delivery." The NYSDOH is structured to optimally serve those populations most in need. Additionally, the NYSDOH maintains a comprehensive local health infrastructure in NYS through its 57 county health departments and the New York City Department of Health and Mental Hygiene.

Sections in PHL article 25 authorize the DOH commissioner to, among other important activities, screen infants for hearing problems (§2500-g). An important asset to Departmental efforts to monitor, evaluate and improve patient care and outcomes is provided by PHL §2500-h, which authorizes development and maintenance of a statewide perinatal data system and sharing of information among perinatal centers. The ability of NYS to regulate hospitals, including ambulatory health facilities, is conferred by PHL Article 28 and is a prime determinant of the Department's capacity to promote and protect the health of mothers and children. In addition, the Department has been given broad powers to regulate home health care agencies and health maintenance organizations through PHL Article 36 and PHL Article 44, respectively.

The NYSDOH is organized structurally into offices that oversee core public health functions for NYS. These offices include the Office of Health Insurance Programs (OHIP), which oversees the state's Medicaid Program; the Office of Quality and Patient Safety (OQPS), which oversees the health, quality of care, and patient safety for all New Yorkers and takes the lead on evaluating Medicaid programs and clinical models of care; the Office of Minority Health and Health Disparities Prevention (OMH-HDP), which works across offices to address health disparities; the Office of Primary Care and Health Systems Management (OPCHSM), which oversees the birthing facilities and hospitals; and the Office of Public Health (OPH), which includes the Center for Environmental Health, which includes the Congenital Malformations Registry, and the Center for Community Health, which oversees the state's critical public health programs, such as WIC, Immunization, Lead Prevention, and Maternal and Child Health Programs, including Title V, Home Visiting, NY EHDI Program and the NYS EIP. In addition,

the NYSDOH Wadsworth Laboratory Center oversees the newborn screening (blood spot) program.

Within the Center for Community Health, Division of Family Health (DFH), BEI administers and oversees the NY EHDI. BEI is also responsible for the administration and oversight of the NYS EIP under Part C of IDEA. The DFH is responsible for the development and oversight of public health activities related to a broad range of maternal and child health issues that are core to the NYSDOH mission and the Title V MCHSBG. The Division of Family Health recognizes and supports the importance of newborn hearing screening and intervention as a priority area for the Division. The Division Director, Lauren Tobias, is the NYS Title V Director. Ms. Tobias has experience in the state's Medicaid Program and Title V MCH programming, and currently heads the NYSDOH leadership team overseeing the six MCHSBG priorities (women/maternal health, perinatal/infant health, child health, children and youth with special healthcare needs (CSHCN), adolescent health, and cross-cutting or life course). Improving follow-up for children with suspected or confirmed hearing loss and increasing access to NYS EIP services are two of the state's priorities under the CSHCN priority area.

The DFH also houses the Bureau of Child Health (BCH), which includes the Children with Special Health Care Needs Program, and the BWIAH, which is responsible for programming directed at the overall care of mothers and infants, including home visiting initiatives and perinatal health. The NY EHDI Program goals and initiatives have been integrated into the Division's work.

DFH has expertise in leading successful quality improvement collaboratives with NYS birthing hospitals through the New York State Perinatal Quality Collaborative (nyspqc.org) and the NY EHDI Program, which improved follow-up rates from 9.1% for births in calendar year 2014 to 43.5% for births in calendar year 2017. The NY EHDI Program will continue to engage and educate audiologists, pediatricians, early intervention staff, providers, and families to improve follow-up rates, as well as referrals to and enrollment in early intervention services.

The NY EHDI Program is unique among EHDI Programs in that it is administered by the NYSDOH BEI, which oversees the state's Early Intervention Program (EIP). The BEI is responsible for oversight of the NYSEIP with more than 40 staff dedicated to administration of the program statewide. The Director of the BEI is represented as in-kind support in the staffing plan. BEI early intervention teams interface with the EHDI Program team.

Research studies, such as seminal work by Yoshinaga-Itano, Sedey, Coulter and Mehl (1998), [6] the Year 2007 Joint Committee on Infant Hearing (JCIH) Position Statement,[7] the 2013 Supplement,[8] and the recently published Year 2019 JCIH Position Statement[9] include best practices related to screening, identification of hearing loss and audiological, medical and educational management of infants and toddlers with hearing loss. These works indicate that linking the Universal Newborn Hearing Screening and Intervention Program with effective provision of early intervention services may decrease the impact of hearing loss on language and other areas of development. The NYSDOH is positioned to maintain this linkage and continue to improve outcomes for children who are DHH and their families.

[6] Yoshinaga-Itano, C., Sedey, A. L., Coulter, D.K., & Mehl, A.L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics,* 5, 1161-1171.
[7] Joint Committee on Infant Hearing (JCIH) (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics.* 120(4) 898-921.
[8] American Academy of Pediatrics (2013). Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child is Deaf or Hard of Hearing. *Pediatrics,* e1324-e1350.
[9] Joint Committee on Infant Hearing (2019). Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Journal of Early Hearing Detection and Intervention*, 4(2): 1-44.