ii. Project Narrative

Introduction

The New Hampshire Early Hearing Detection and Intervention (EHDI) Program is pleased to apply for funding to develop a comprehensive and coordinated statewide EHDI system. The EHDI system targets ensuring that infants receive appropriate and timely services including screening, diagnosis, and enrollment into early intervention. The EHDI Program is housed within the Maternal and Child Health Section of the Bureau of Population Health and Community Health Services, Division of Public Health Services, New Hampshire Department of Health and Human Services. The EHDI Program began its work in newborn hearing screening in 2000. Over the past 19 years, the program has advanced and is well positioned to continue activities focused around maintaining a 98% screening rate, timely diagnostic completion, increasing health professionals' engagement and knowledge, improving access to early intervention services and language acquisition, and improving family engagement, partnership, and leadership within the EHDI program system.

The EHDI Program has a full-time (1 FTE) EHDI Program Coordinator, a half-time (.5 FTE) Program Specialist, a contracted part-time Consulting Audiologist, and a part-time (.3 FTE) nurse Follow-up Coordinator. The Program Coordinator, Courtney Keane, has her Masters in Health Education and Promotion. She previously worked as the Childbirth Education Program Coordinator and as a licensed nursing assistant on a maternity unit in the largest birth hospital in New Hampshire. Ms. Keane is responsible for all the programmatic and grant requirements of the program. The newly hired Program Specialist, Carolyn Fredette, MPH, previously worked in Vectorborne Disease for the State of New Hampshire. Her work involved surveillance of vectorborne diseases including in addition to health promotion and prevention activities. Ms. Fredette is responsible for monitoring all entries into the data tracking system to assure that all infants are entered by birth hospitals, midwives and diagnostic centers. She is also responsible for requesting and entering data on infants' screening and diagnostic results. She imports and exports data from the newborn hearing screening tracking system (Auris) to and from the vital records application. The contracted Consulting Audiologist, Dr. Mary Jane Sullivan, provides education and support to the audiologists who test infants. She also provides training to the staff at the birth facilities. This includes all hospital newborn hearing screening staff and the certified midwives at three (3) freestanding birth facilities. The Follow-up Coordinator, Suzann Beauregard, RN, previously worked in the areas of pediatrics, family practice, chronic disease management, medical malpractice and personal injury for the past 25 years. Ms. Beauregard uses Auris to identify infants who did not pass their final hearing screening and reaches families by letters and telephone calls to assist them in obtaining and completing diagnostic testing before the infant is three (3) months old. She also ensures that infants who are diagnosed with a hearing loss are referred and enrolled into early intervention. She provides resources to families after being diagnosed with a hearing loss.

The EHDI Program aims are reflected in the goals, objectives and activities of the workplan/logic model (See Attachment 1). The goals and objectives in the work plan are: maintain a 95% or higher screening rate, increase or maintain an 85% or higher diagnostic completion by three (3) months of age, increase or maintain an 80% or higher enrollment into early intervention by six (6) months of age, increase the number of families enrolled in family to family support,

increase the number of families who are enrolled in adult to family support services by nine (9) months of age, and increase the percent of health professionals knowledge around timely referral to diagnostics and enrollment into early intervention. The EHDI Program has and will continue to use the Model for Improvement (Plan-Do-Study-Act) developed by Associates in Process Improvement to improve outcomes for all newborn hearing screening activities in New Hampshire.

Needs Assessment

New Hampshire is one of the oldest states in the country; it was originally a land grant in 1623 and became a state in 1775. New Hampshire's population of 1.36 million live in 9,351 mostly forested (81%[1]) square miles bordered by Canada on the north and by Massachusetts on the south. On the east is the Atlantic Ocean and Maine and on the west is Vermont. The state's landscape lends itself to many different types of outdoor recreation. However, that same topography lends itself to difficult driving and long distances between places, particularly in the winter months.

With its ten counties, approximately 47% of the population and 84% of the landmass in New Hampshire is considered rural; most of the land area lies north and west of the capital Concord. The three (3) most urban or metro areas are Manchester, Nashua and Concord, all located in the state's southern tier where the majority (53%) of the population lives. The state's population is primarily white (94%), but its residents of color are increasing.[2] The citizens in rural communities face geographical barriers to access health care such as lack of transportation, increased travel time to health care providers, hospitals, and early intervention agencies.[3] It is important to provide support to communities and stakeholders and provide innovative and effective ways to increase access to quality healthcare services and early intervention services with a focus on infants who are deaf or hard of hearing and their families as well as reducing the barriers associated with access to quality healthcare services and early intervention services.

The 2019 KIDS COUNT data book by the Annie E. Casey Foundation ranked New Hampshire in the top ten for overall child well-being, economic well- being, education, and health. However, rank along does not paint a complete picture of how children in New Hampshire are faring. New Hampshire has often been in the top tier in rankings of its overall well-being and in

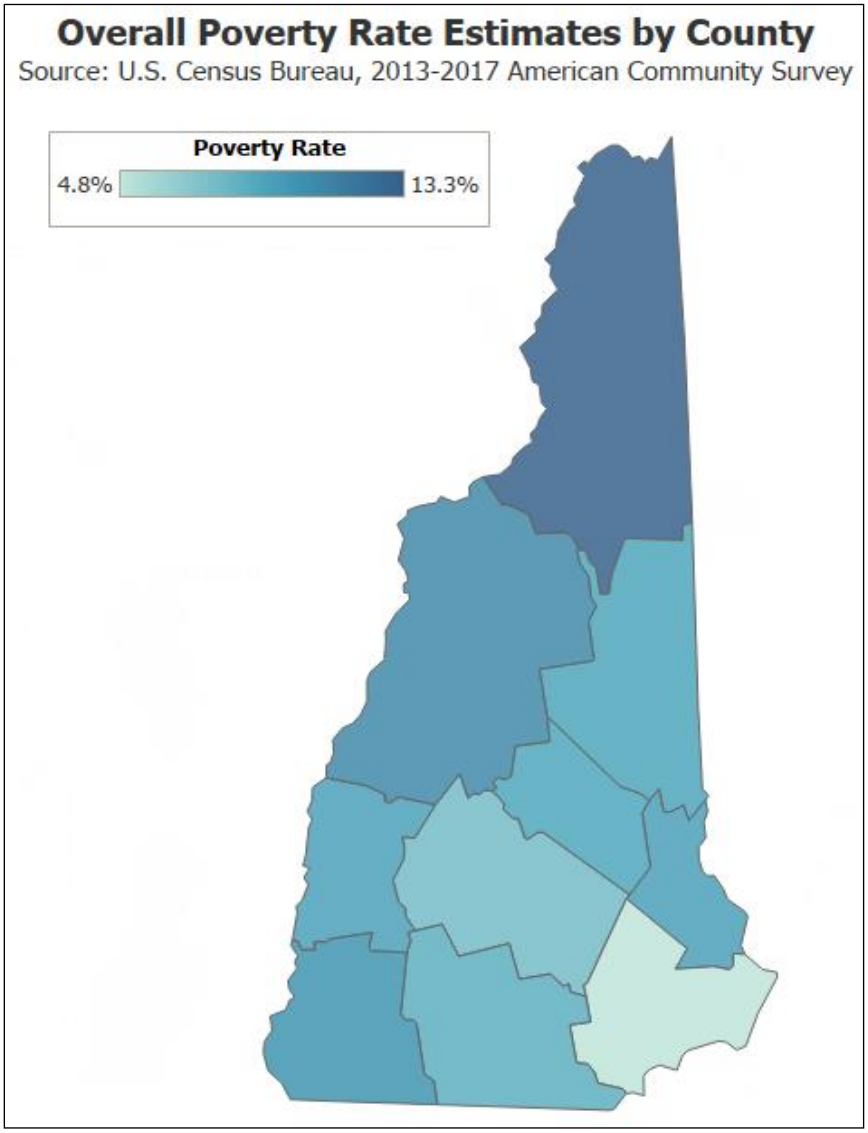
[1] Division of Forests and Lands, New Hampshire Department of Natural and Cultural Resources. Retrieved on 05/26/2019 from https://www.nhdfl.org/reports/forest-statistics.
[2] United States Census Bureau (2019). *Quick Facts New Hampshire*. Retrieved on 05/26/2019 from https://www.census.gov/quickfacts/fact/table/NH/POP815217#POP815217.
[3] NH DHHS DPHS Rural Health and Primary Care section, 2015

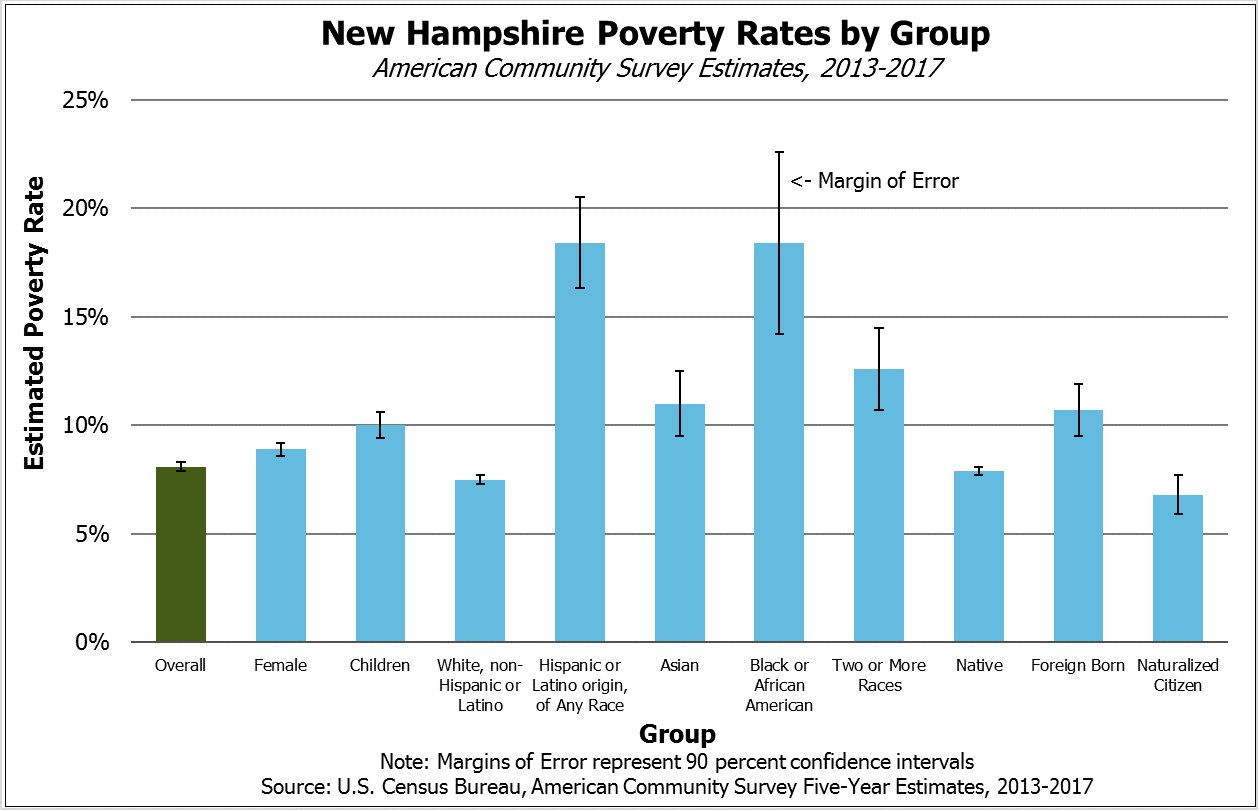
the social determinants of health[4,5,6,7,8,9] however, disparities can be hidden in average rates. There are two areas of concern for New Hampshire: poverty rate and child health.

New Hampshire's poverty rate is 7.7%.[10] The rates vary across the state with numbers increasing the further away from the more population dense areas in the southern part of the state. Geographic poverty disparities are greatest among children with about one in five children in Coos County (the Northernmost and only county significantly different than all the others) and one in 17 estimated to be living poverty in Rockingham County (the most heavily populated and in the South). [11] Differences also exist among age, racial/ethnic groups and family composition.[12] There are also geographic disparities to health care such as the greater distances to services and lower provider availability.

[4] Commonwealth Fund, (2019). 2019 Scorecard on State Health System Performance. Retrieved on 06/12/19 from https://scorecard.commonwealthfund.org/.
[7] Annie E. Casey Foundation (2018). *2018 Kids Count Data Book: State Trends In Child Well-Be*ing. Retrieved on 06/06/2019 from https://www.aecf.org/m/databook/2018KC_profiles_NH.pdf.
[8] United Health Foundation (2018), *America's Health Rankings*. Retrieved on 06/07/2019 from https://assets.americashealthrankings.org/app/uploads/2018ahrannual_020419.pdf.

[7] United Health Foundation (2019), *America's Health Rankings*, *Senior Report*. Retrieved on 06/07/2019 from https://assets.americashealthrankings.org/app/uploads/ahr-senior-report_2019_final.pdf.
[8] McCann, A. (2019). *Best and Worst States to Have a Baby*. Retrieved on 06/07/2019 from https://wallethub.com/edu/best-and-worst-states-to-have-a-baby/6513/#methodology.
[9] U.S. News and World Report (2019). *Best States 2019*. Retrieved on 06/07/2019 from https://www.usnews.com/news/best-states/new-hampshire.
[10] United States Census Bureau (2019). *Quick Facts New Hampshire*. Retrieved on 06/11/19 from https://www.census.gov/quickfacts/fact/table/NH/PST045218.
[11] New Hampshire Fiscal Policy Institute (2018). New Hampshire's Numbers: Disparities Between Counties and Populations Persist: 2013-2017. Retrieved on 06/12/19 from http://nhfpi.org/research/state-economy/new-hampshires-numbers-disparities-between-counties-and-populations-persisted-in-2013-2017.html.
[12] Ibid.


Overall Poverty Rate Estimates by County
Source: U.S. Census Bureau, 2013-2017 American Community Survey
Poverty Rate
4.8%
13.3%



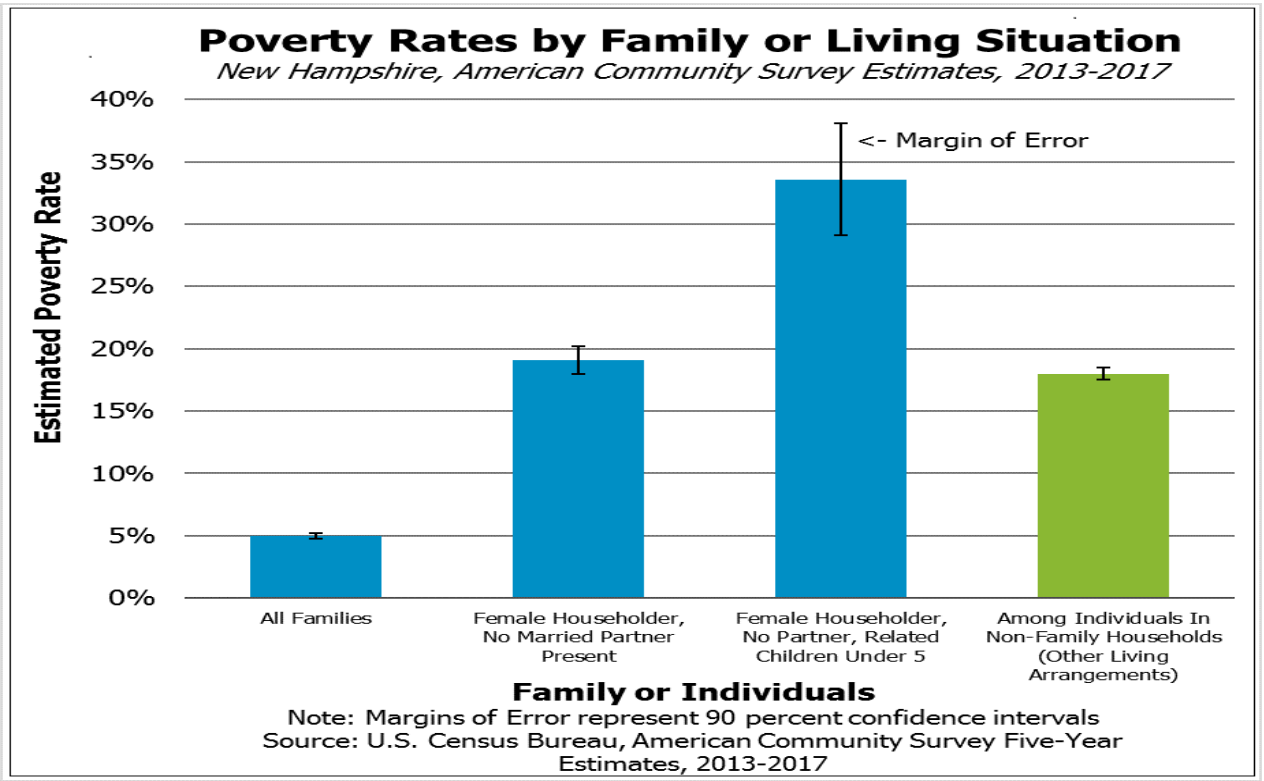


Table I: Data on Maternal Ethnicity and Race from 2013 to 2015

Maternal Ethnicity	**2016**	**2017**	**2018**	**Total**
Hispanic or Latino	408	394	419	1221
Not Hispanic or Latino	11674	11455	11249	34378
Unknown	105	92	177	374
Maternal Race	**2016**	**2017**	**2018**	**Total**
White (Not Hispanic)	10599	10416	10228	31243
White (Hispanic)	75	108	119	302
White (Ethnicity Unknown)	0	0	0	0
African American (Not Hispanic)	182	219	235	636
African American (Hispanic)	9	4	15	28
African American (Ethnicity Unknown)	0	0	0	0
Asian	336	346	309	991
Native Hawaiian & Other Pacific Islander	4	2	0	6
American Indian & Alaskan Native	0	0	0	0
Unknown	919	846	939	2704
Other	0	0	0	0

*Data in the chart above is from the EHDI database system, Auris.

With concerns for overall child health, New Hampshire Medicaid utilizes a managed care model for Medicaid serves as of 2013. There are currently three (3) managed care organizations (MCOs), Well Sense, New Hampshire Healthy Families, and AmeriHealth Caritas. In April 2019, approximately 178,012 New Hampshire residents, nearly 13% of the state's population were on Medicaid. Children continue to make up the greatest proportion.

It is evident that socioeconomic status, maternal demographic data and health care status are interconnected. When poverty and poor health are present, children are at a higher risk for a host of life-long adverse outcomes. However, there are actions that can be taken to minimize poor outcomes. While fewer children in New Hampshire face these risks compared to other parts of the country, there are still geographic, racial, ethnic and economic disparities that cannot be ignored.

New Hampshire is one of the nation's least diverse states, though is growing. Nationally the non-Hispanic white population declined from 69.1 percent to 60.6 percent, a drop of about 8.5 percent between 200 and 2017. In New Hampshire the share dropped from 95.1 percent 90.3 percent a decline of 4.8 percent that was only about half the national drop and one for the smallest drops in the country. Thus, though the relatively small minority population doubled from 61,000 in 2000 to 130,000 in 2017 and accounted for two-thirds of the small increase in the entire population, the impact on overall make up of the state was relatively small compared to other states. In New Hampshire, Hispanics are the largest minority in the state with a population of 50,300 residents. The Asian population is about 35,600 residents and African American with 18,000. Each of these three (3) groups nearly doubled in size between 2000 and 2017. Children

are in the vanguard of the states growing diversity, due predominantly to the decline in births among non-Hispanic white. In all, 14 percent of New Hampshire's children belong to a minority population in 2016.[13] Limited English Proficiency (LEP) found in only one percent of the state's overall population, predominantly concentrated in the non-rural parts of the state. Health care providers in New Hampshire have responded to these changes by offering more options to meet the needs of parents from minority groups. New Hampshire organizations provide translation services and interpreters for clients who use other languages, including American Sign Language.

New Hampshire is one of the few states that does not have legislation mandating newborn hearing screening. However, in 2018, the New Hampshire Joint Legislative Committee on Administrative Rules adopted rules that require any facility or audiologist conducting newborn hearing screening or a diagnostic test to report the results to the EHDI Program for the birth to three (3) population. In 2016, the New Hampshire licensure for hearing added to the audiologists' licensure to report any hearing screens or diagnostic tests, on children birth to three (3), to be reported to the EHDI Program.

The EHDI Program has made significant progress on the national goals for newborn hearing screening: complete hearing screen by one (1) month of age; complete diagnostic testing by three (3) months of age; and enrollment in early intervention by six (6) months of age. In 2018, 98% of infants born in New Hampshire were screened by one (1) month, of infants screened 3% referred on the final (second) hearing screen, 57% completed diagnostic testing by three (3) months and 38% enrolled into early intervention by six (6) months of age.

By providing young children with a healthy start and positive early learning experience it fosters an environment in which each child can reach their full potential. Hearing loss can adversely affect speech and language development as well as academic and social-emotional development. How a child learns to play, speak, act and move provides insight on the child's development. The brain is the true organ of hearing; ears only submit the sound to the brain. Babies born with a hearing loss are not starting at the same point as infants born with typical hearing. The American Academy of Audiology Childhood Hearing Screening Guidelines states that hearing loss is the most prevalent developmental abnormality present at birth. [14] Early identification of hearing loss, by six (6) months of age, in combination with quality and appropriate early intervention services is associated with language development at or near the typical rate of development.

The birth to three (3) population has had both its successes and challenges in screening, diagnostic testing completion and enrollment into early intervention, if needed. The EHDI Program for the past five (5) years has maintained a 98% screening rate. This is a vast success because as mentioned above, New Hampshire does not have legislation mandating newborn hearing screening. However, the EHDI Program has challenges with infants completing diagnostic testing by three (3) months of age due to diagnostic center capacity. In 2018, two (2) of the four

[13] University of New Hampshire, Carsey School of Public Policy
[14] America Academy of Audiology
http://www.cdc.gov/ncbddd/hearingloss/documents/AAA_Childhood%20Hearing%20Guidelines_2011.pdf

(4) diagnostic centers on the EHDI approved list no longer see/accept the birth to three (3) month population, due to audiologists relocating. With the closing, it has placed a back log on the other two (2) centers. The EHDI Program plans to pilot with one (1) diagnostic center prioritizing infants who did not pass bilaterally. There are discussions with stakeholders around infants who unilaterally do not pass and if a diagnostic screen can be done instead of a full diagnostic test. The diagnostic screen would include automated ABR, click ABR at 30 dBHL using diagnostic equipment (interpretation required), with the optional tympanometry (1kHz) and OAE screen if infant sleep state allows. The EHDI Program recognizes that this is not best practice and a full diagnostic test should be completed but due to the diagnostic center capacity the EHDI program, with involvement of stakeholders, is exploring alternative options for the interim. However, if an infant does not pass the audiologist screen a full diagnostic test should be scheduled for 2-3 weeks after the diagnostic screen, which would meet the criteria for JCIH standards.

Another success and challenge is enrolling infants who are diagnosed with a hearing loss into early intervention by six (6) months of age. Overall New Hampshire has a 60% enrollment into early intervention. Due to diagnostic center capacity New Hampshire struggles enrolling infants into early intervention by six (6) months. This is due to infants not being diagnosed until after three (3) months of age. New Hampshire collaborates with Part C, early intervention, to develop a system to obtain infants individual family service plan (IFSP) date and referral to early intervention. The EHDI Programs goal is to have a continuous document with updated status on infants IFSP referral and enrollment into early intervention. The EHDI Program will continue to work with Part C to identify both successes and challenges regarding referral and enrollment into early intervention.

Methodology

The EHDI Program is made up of a Program Coordinator, Program Specialist, and a Follow-up Coordinator. The Program staff equals 1.8 FTE, whom are all employees of the New Hampshire Division of Public Health Services (See Attachment 2, Job Descriptions, Attachment 3, Biographical Sketches, Attachment 5 Project Organizational Chart and Attachment 7 Resumes). The program has two contracts; a Consultant Audiologist and a Family Organization. The contract with the Family Organization is with Northeast Deaf and Hard of Hearing (NDHHS). NDHHS supports deaf and hard of hearing mentorship through adult to family support and family to family support. The contract for the consulting audiologist is with Dr. Mary Jane Sullivan. Dr. Sullivan supports diagnostic centers in policies, procedures, and referral processes for infants identified as deaf or hard of hearing. All members of the EHDI team participate in staff training and professional development activities. The Program Coordinator, Consulting Audiologist, and a parent representative annually attend the annual EHDI national meeting. If funds allow, the EHDI Program supports additional staff to attend the national conference. The EHDI team updates key stakeholders with program newsletters, emails, meetings and conference calls as needed.

The EHDI Programs goals and objectives are reflected in the workplan (See Attachment 1). The goals and objectives in the work plan: maintain a 95% or higher screening rate; increase or maintain an 85% or higher diagnostic completion by three (3) months of age; increase or

maintain an 80% or higher enrollment into early intervention by six (6) months of ag;, increase the number of families enrolled in family to family support, increase the number of families who are enrolled in adult to family support services by nine (9) months of age; and increase the percent of health professionals knowledge around timely referral to diagnostics and enrollment into early intervention.

The EHDI Program continues to use the Model for Improvement (Plan-Do-Study-Act) developed by Associates in Process Improvement to improve outcomes for all newborn hearing screening activities in New Hampshire. Quality Improvement strategies include: 1) Data review of initial entry into the EHDI system; 2) Birth facilities to directly fax all infants who do not pass the final hearing screen to the EHDI Program within 48-72 hours: 3) EHDI Program to fax infants PCP/Pediatrician infants screening result with date of diagnostic appointment prior to infants one (1) month well child check: 4) Inform PCP/Pediatricians infants who missed, cancelled, or EHDI is unable to reach the family: 5) Fax to PCP/Pediatrician infants' diagnostic results and recommendations for follow up: 6) Pilot with 1-2 hospitals referring to a diagnostic center bilateral did not pass for a full diagnostic testing and referring unilateral did not pass for a diagnostic center screen: 7) Streamline early intervention enrollment and referral; 8) Analyze and improve data,; 9) Develop an online resource center for health care professionals and families to use as a guide and 10) Improve resources through parent and family organizations input.

The EHDI QI Committee meeting meets three (3) times a year. The dates and times vary to accommodate stakeholders. Meetings are typically held in March, June, and October/November. The EHDI Program recruits members for the Quality Improvement (QI) Committee. Stakeholders and partners include:

Parent Representative
New Hampshire Family Voices
New Hampshire Hands and Voices
Part C
Early Intervention Provider
Audiologists
American Academy for Pediatrics Chapter Champion
Northeast Deaf and Hard of Hearing Representative
Hospital Nurse/Nurse Manager
Midwife

The meetings focus around the EHDI Programs goals and objectives in order to improve outcomes for infants who do not pass the newborn hearing screening and need further audiological evaluations and, if needed, referral to early intervention. EHDI QI meetings include, but are not limited to identifying change in strategies, working with diagnostic centers to conduct PDSA cycles to improve timeliness of diagnostic testing, analysis of results to determine if the change results in improved outcomes, and testing of successful strategies on a larger scale.

The EHDI Program adopted Administrative rules in 2018 to include reporting of infants/children up to the age of three (3). New Hampshire foresees obtaining infants' diagnostic

testing results from audiologists up to the age of three (3) to be a learning experience and also an opportunity to engage and collaborate with practices who see children over the age of six (6) months for diagnostic testing. Currently, the main reporting of birth to three (3) years old is done by the EHDI approved diagnostic centers. With the expansion of reporting to age three, New Hampshire plans to engage other practices who see children over a year. New Hampshire is unique in that there are very few audiologists who have the expertise to complete a diagnostic testing on a birth to three (3) month old.

The EHDI Program plans to utilize the consulting audiologist, AAP Chapter Champion, and members of the QI team to identify, develop, implement and evaluate a process for children over the age of one who are diagnosed with a hearing loss by the end of year two (2) of the project period. The EHDI Program plans to develop a protocol for audiologists to follow for reporting to the EHDI Program a newly identified child who is deaf or hard of hearing.

As mentioned previously and in the workplan, the EHDI Program plans to develop/update the State of New Hampshire's website to include two (2) additional sections focused on health care providers. The website sections will be for audiologists and physicians. Each section will include resources for practitioners on JCHI standards, reporting to the EHDI Program, resources for families, frequently asked questions, "ask an audiologist", "ask the AAP Chapter Champion" and a general overview of New Hampshire EHDI.

The EHDI Program supports NDHHS to carry out deaf and hard of hearing family to family support and adult to family support for families who have an infant/child who is deaf or hard of hearing. NHHDS interviewed and selected sixteen individuals to participate in Snapshots, a curriculum from the SKI-HI institute to support families through their journey. Participants learned how to provide families unbiased information regarding language modalities, how to share their story, deaf culture, and hearing devices. Every family's journey will be different and sharing their experiences (challenges and success) is beneficial to families trying to navigate through the system. The process for referring families to family support or adult to family support is in development, with a goal of January 2020 for an implementation.

The EHDI Program was established 19 years ago. The EHDI Program is federally funded by the Health Resources and Service Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). The program does not provide any funding to birth facilities' newborn hearing screening programs or pediatric diagnostic centers. However, the EHDI Program has purchased hearing screening equipment for birth centers and midwives to be able to screen infants who are born outside of the hospital. The EHDI Program provides consultation, education and monitoring of newborn screening and diagnostic testing activities. The EHDI team oversees all newborn hearing screening activities and diagnostic testing activities at all 17 birth hospitals, three (3) birth centers, two (2) pediatric diagnostic centers and five (5) midwives. If grant funding is discontinued, Title V funding, newborn bloodspot screening funding, or other resources within the Department of Health and Human Services may be used to support the activities of the EHDI Program.

Workplan

Please see attachment 1 for workplan/logic model.

Resolution of Challenges

New Hampshire is a small state based on population and geographic area. Its residents have historically shared good health outcomes. Newborn hearing screening is not legislatively mandated, yet over 98% of newborns received newborn hearing screening in 2018. Part of this success can be attributed to the EHDI Program staff and consultants who have developed close working relationships with birth facility personnel and audiologists. The EHDI Program does experience challenges such as limited resources, lack of pediatric audiologists, and limited early intervention service providers for infants who are deaf or hard of hearing.

The majority of women deliver their newborn in the southern part of the state. Midwives attend approximately 250 births each year; half are born at freestanding birth centers and the other half at home. Both offer newborn hearing screening for infants. The EHDI Program provides equipment and supplies to birth centers and five (5) midwives. The EHDI Program Coordinator and Consulting Audiologist have collaborated with the midwives at the freestanding birth centers to provide education and promote newborn hearing screening. The EHDI Program continues to have challenges with individual midwives and compliance on newborn hearing screening, particularly ones who live in the northern part of the state. The EHDI Program has also had challenges with one birth center not consistently screening and reporting hearing screen results. If noncompliance continues, the hearing screening equipment will be asked to be returned to the EHDI Program and redistributed to another midwife who is willing to screen and report results.

The EHDI Program does not offer financial support to birth hospitals newborn hearing screening programs, audiological diagnostic evaluations, or early intervention services. The EHDI Program does contract with a family organization, NDHHS to carry out deaf and hard of hearing mentorship activities as well as resources for families. Hospitals, birth centers, and pediatric diagnostic centers use their own resources to enter data into Auris. New Hampshire is currently in the process of publishing and posting a Request for Proposal (RFP) for an integrated data management system. The integrated data management system is to expand capacity within the maternal and child health section to capture data on newborn hearing screening, newborn screening (blood spot), birth conditions, and critical congenital heart disease. The RFP is to seek a scalable, secure web based health data management solution for the programs listed above with the flexibility to add new fields/modules as necessary. The secure web based health data management system must be able to interface with other state data systems, special screening devices, electronic medical records (EMR), and screening laboratory using established health data exchange standards. By publishing this RFP, the EHDI Program hopes to improve timeliness and accuracy of reporting of results. With this potential change in the reporting system, the EHDI program anticipates successes and challenges during the process. Successes include timely and accurate data being reported, utilizing EMR transfers using data exchange standards, and a decrease at the hospital level of personnel for data entry. Challenges that might occur include initial delays in

obtaining infants' results, developing a process with hospitals for reporting results, and dealing with technical issues that arise during the process of transition. With these potential challenges, the EHDI program will work closely with hospital data entry personnel in the upcoming grant cycle.

A challenge has been diagnostic centers and timely reporting of diagnostic evaluations. In the past, audiologists have improved data entry on diagnostic results but have lacked entering missed/cancelled appointments. Activities in the workplan, Include a pilot with 1-2 hospitals for referring bilateral did not pass for a full diagnostic testing and referral a diagnostic screen for unilateral did not pass. The EHDI Program recognized that there are challenges associated with this pilot but is hopeful. Challenges include, protocol, billing for a diagnostic screen, appointment times (length), and data entry errors prior to diagnostic screening appointment. Success could potentially include, decreased wait time at diagnostic centers, shorter appointments for families, and an increase of infants who complete audiological follow up.

In the past years, the Follow-up Coordinator and audiologists have both referred infants who were identified with a hearing loss to early intervention. This has been a challenge when trying to obtain an infant Individual Family Service Plans (IFSP) dates from Part C. Activities, in Goal three (3) are focused around streamlining the referral to early intervention through the Follow-up Coordinator. By streamlining the process, the EHDI Program will know who and when the referral to Part C was made. This helps increase the EHDI Programs ability to collaborate with Part C for developing and maintaining a document for status of infant's referral and enrollment into early intervention services.

The EHDI Program plans to work with NDHHS to develop educational resources for families and a referral system for enrolling families in support services. Activities in goal four (4) aim to develop, implement and evaluate the family to family/adult to family support services. Since this is new to the EHDI Program, it is unknown what the successes and challenges will be.

Evaluation and Technical Support Capacity

The EHDI Program has the resources and capacity to continue to support parents through family to family support/adult to family support, birthing facilities, diagnostic centers, and early intervention by providing systems development, audiology consultation services, and educational resources for parents and professionals. The EHDI system development includes reporting mechanisms, referral process for diagnostics and follow up for infants identified as deaf/hard of hearing; educational resources include a resource book for parents, links to local, state, and national resources available on the New Hampshire DHHS website, and social media messages through both New Hampshire DHHS tweets and press releases. Audiology consultation includes assisting new diagnostic centers in developing processes and policies for diagnostic testing and referrals to specialists if needed.

The EHDI information system, Auris, captures data on all infants born in New Hampshire. These data fields are critical for monitoring of individual newborn hearing screening results and

tracking of infants who need further audiological follow-up. Auris reports allow EHDI staff and consultants to analyze and track data to measure change strategies. Staff monitors individual data quality to ensure that all infants born in New Hampshire are captured in Auris, through matching of Vital Records. The EHDI Program staff monitors data for completeness and accuracy of individual data entry. Staff utilize the data and reports to drive evaluation activities and monitor program performance related to newborn hearing screening by one (1) month of age, diagnostic evaluation by three (3) months of age, and enrollment in early intervention by six (6) months of age.

Rhonda Siegel, MEd, serves as the MCH Section Administrator and oversees the MCH section. Courtney Keane, MS, serves as the project director and manages the day-to-day operation of the EHDI Program and all the grant reporting requirements. The day-to-day operations include monitoring hospital programs, diagnostic center issues and concerns, and collaborating with Part C for infants' enrollment into early intervention. Ms. Keane provides feedback to hospital staff about screening rates, timeliness of data entry and timeliness of referral to diagnostic centers. Carolyn Fredette, MPH, oversees the data entry aspects of the EHDI Program. She contacts birth facilities to obtain any incomplete data or omissions. Suzann Beauregard, RN, Follow-up Coordinator, supports families whose infants did not pass their final hearing screening and assists them in scheduling diagnostic testing for their infants. Dr. Mary Jane Sullivan, Au.D CCC-A, Consulting Audiologist, focuses on policy and process of diagnostic centers. Please see Attachment 2: Job Descriptions for Key Personnel and Attachment 3: Biographical Sketches of Key Personnel for additional details.

Programs throughout the Division of Public Health Services have used performance measures for contracts with agencies throughout New Hampshire for many years. Since the implementation of the Auris tracking system in 2004, the EHDI staff has used performance measures to evaluate the birth facility newborn hearing screening programs and help program managers identify areas for improvement. The EHDI Program, in this grant cycle, will develop of a set of performance measures for diagnostic centers and Part C.

New Hampshire continues to maintain a 98% screening rate. This has been achieved by birth facilities having screening protocols and staff having to take an annual competency test. All protocols are different based on the equipment that the birth facility use, Otoacustic Emissions (OAE) or Auditory Brain Response (ABR). All birth hospitals in New Hampshire use the ABR equipment. Birth Centers and Midwives use OAE equipment.

New Hampshire has approximately 400 or 3% of infants who do not pass on the final newborn hearing screen. Since 2004, hospitals have been reporting hearing screening results in Auris. Since 2006, audiologists have been reporting diagnostic center results in Auris. Shown in Table II, are the percent of newborns who did not pass on the final screen and who completed diagnostic evaluations by three (3) months, and those over three (3) months for the past three years.

Table II: Data on Diagnostic Completion from 2016 to 2018

Year	Number of Diagnostic Centers	Number of Births	Number of infants referred	Completed Diagnostics by 3 months	Completed Diagnostics (over three months)	Total Completed Diagnostics
2016	3	12,241	3.4% (407)	56% (228)	19 % (78)	75% (306)
2017	3	12,000	3.2% (394)	51% (201)	24% (95)	75% (296)
2018*	3	11,956	3.2% (393)	57% (224)	23% (91)	80% (315)

*Data is from the Auris database system, some 2018 data is in process as 2018 has not been officially closed.

Evaluation activities will focus on timely diagnostic testing completion, timely referral to early intervention, and timely enrollment into early intervention. The Evaluation questions that New Hampshire will explore are:

1. Does engaging the medical home provider increase the percent of infants who complete diagnostic testing by three (3) months of age?
2. Does engaging the medical home provider decrease the percent of families who miss/cancel diagnostic appointment?
3. Does timely diagnosis lead to timely referral to early intervention for infants diagnosed with a hearing loss?
4. Does engaging the medical home increase the number of families who complete diagnostic testing and if needed, enrollment into both family supports and early intervention services?

Table II depicts an overall increase in infants who completed diagnostic testing, but also reflects a maintained percent of completion of diagnostic testing by three (3) months of age. The table also reflects that the percent of infants who referred on the newborn hearing screening has stayed the same over the past three (3) years. The EHDI Program has shifted its focus from screenings to diagnostic completion. The EHDI Program continues to work with birth hospitals and birth centers to maintain a 98% screening rate, but aims to focus on improved timely diagnostics which impacts timely referral to early intervention.

In 2017, the EHDI Program implemented having birth hospitals directly fax, within 48-72 hours, infants who did not pass their final newborn hearing screening. In 2018, the EHDI Program began faxing infants screening results followed by infants' diagnostic results to the PCP/Pediatricians office. With no significant increase in infants completing diagnostic results by three (3) months of age, the EHDI Program noticed an overall increase (5%) in completion of diagnostic testing between 2017 and 2018. Although this is not a significant increase, the EHDI Program is hopeful that by engaging the medical home provider early on in the process that families will continue to complete diagnostic testing. As mentioned above some of the challenges are due to diagnostic center capacity.

Of the 315 infants who received a diagnostic evaluation in 2018, 17 had documented permanent hearing loss. In the past, it has been a challenge to obtain IFSP dates, but with continued collaborative efforts between EHDI and Part C, obtaining IFSP dates should increase in future

years. Evaluation activities that increase the percent of infants who enroll in early intervention by six (6) months of age will focus on referrals made by the Follow-up Coordinator to early intervention programs. The EHDI Program and Part C are developing a tracking mechanism for infants who have been referred. The mechanism will include referral date, agency, tentative evaluation date, and a comments section. This way, the EHDI Program Coordinator can track where the family is in the process of enrollment. Collaboration with Part C, audiologists, the Follow-up Coordinator and area agencies will be instrumental in obtaining the IFSP date.

For all of the evaluation questions, engagement by stakeholders is critical in improving the outcomes of infants completing diagnostic testing by three (3) months, timely referral to early intervention, and timely enrollment into early intervention. Strategies to be used include PDSA cycles, QI activities, monitoring data, engaging the medical home, care coordination and engagement by stakeholders.

Organizational Information

The EHDI Program is housed within the New Hampshire Title V Program in the Maternal and Child Section (MCH) of the Bureau of Population Health and Community Services, Division of Public Health Services (DPHS), Department of Health and Human Services (See Attachment 5). The Mission of DPHS is to assure the health and well-being for all people in New Hampshire by protecting and promoting physical, mental and environmental health and by preventing disease, injury and disability. Its vision is to be a responsive, expert, leadership organization that promotes optimal health and well-being for all people in New Hampshire and protects them from illness and injury.

It is MCH's goal that every child in New Hampshire has the opportunity to grow up healthy. MCH has been devoted to administering programs and services for women, infants and children. It supports a broad array of programs in order to improve the availability of and access to high quality preventive and primary health care for all children and to reproductive health care for all women and their partners regardless of their ability to pay. It is supported in part by Title V funds. Priorities are based on a yearly review of statewide need, which is reported on in MCH's annual Title V HRSA Grant Application.

MCH is well positioned to continue newborn hearing screening activities in New Hampshire. Expertise within MCH includes nurses, health educators, early childhood experts, public health professionals, epidemiologists, and program evaluation specialists. MCH staff work as a multi-disciplinary team and are available to provide assistance to EHDI staff as they assure that all newborns born in New Hampshire are offered hearing screening, and maintain systems for assuring appropriate diagnosis and follow up with infants who are identified as deaf or hard of hearing.

There are several related programs within MCH that have a wealth of expertise in the screening and follow up of infants and children with health conditions. The Newborn Screening

Program carries out a variety of activities including: mandated testing of all newborns statewide for various inherited conditions; tracking of test results; initiating follow up with primary care providers for confirmatory testing; and working to assure timely interventions for newborns who test positive. The New Hampshire Sudden Unexpected Infant Death (SUID) Project, funded by the Centers for Disease Control and Prevention, monitors and tracks data related to infants who die suddenly and unexpectedly, and works with a variety of health professionals on a state and local level to reduce risk factors, improve access to services, and change policies to prevent further deaths from occurring. The Pregnancy Risk Assessment Monitoring System (PRAMS), a surveillance project, funded by the Centers for Disease Control and Prevention. PRAMS collects state-specific, population based data on maternal attitudes and experiences prenatally and shortly after birth to improve the health outcomes of mothers and infants. The Home Visiting Program, funded by the Health Resources and Services Administration, targets high risk pregnant women to provide education prenatally and postpartum for both mother and infant to improve health outcomes.

The EHDI Program can draw on the expertise and assistance of its Title V sister organization, Special Medical Services, New Hampshire's agency for Children with Special Health Care Needs. Special Medical Services has a long history of providing care coordination for children with chronic conditions. Staff from Special Medical Services is available to provide care coordination and financial assistance for income-eligible families, including families of children identified as deaf or hard of hearing. Housed, physically, within the Special Medical Services, is NH Family Voices, which also works closely with the EHDI Program. One of the Co-Directors of NH Family Voices is a member of the EHDI Program Quality Improvement Committee. In 2019, Hands and Voices official became a chapter in New Hampshire. The EHDI Program plans to engage Hands and Voices in the QI committee as well as in other aspects of the EHDI Program that support family to family/adult to family supports.

The entire EHDI Program staff and consultants have developed close working relationships with hospital newborn hearing screening personnel, audiologists, and Part C. The EHDI staff continues to assist the hospital newborn hearing screening managers to identify areas needing improvement and monitor the progress of each hospital program. However, the EHDI Program's focus has shifted from screening to diagnostic completion and referral and enrollment into early intervention. The goals are to increase the percent of infants who complete diagnostic testing by three (3) months of age and enrollment into early intervention by six (6) months of age. The EHDI Program also plans to address the goals of increasing the number of families who are enrolled in a family to family support services no later than six (6) months of age, increase the number of families enrolled in a deaf and hard of hearing adult family to family support services no later than nine (9) months of age, and increase the percent of health professionals and services providers who are knowledgeable and trained in the EHDI Program.

As presented in the Needs Assessment portion of this proposal, New Hampshire does not have legislation requiring newborn hearing screening. As stated is that the New Hampshire Joint

Legislative Committee on Administrative Rules adopted rules in 2018 that require anyone conducting newborn hearing screenings or diagnostic hearing evaluations results to report the results to the EHDI Program on the birth to three (3) population. It should be noted that despite the lack of a legislative mandate, all hospitals with birth facilities offer newborn hearing screening. In 2018, 98% of infants born at a New Hampshire birth facility had a newborn hearing screening.

The EHDI Program has the resources and capabilities to support the provision of culturally and linguistically competent and health literate services. EHDI Program materials are written for low literacy levels. The materials that are provided to the birth facilities on referrals are in both English and Spanish. The Department of Health and Human Services utilizes the Office of Minority Health and Refugee Affairs (OMHRA), which has the ability to get written documents translated upon request. OMHRA provides information and services for interpretation, translation, deaf/hard of hearing and other communication access resources. This includes over the phone interpretation, a language bank web portal, low vision resources, and the ability to get written documents translated upon request. Interpreter services are available for non-English speaking families, and access to a TTY line is available for hearing impaired parents. For the EHDI Program stakeholder meetings, the program is able to utilize the services of interpreters to sign through the Language Bank.

The unique needs of target populations of the communities served by this grant are routinely assessed and improved. In addition to the annual review of demographics for the Title V MCH federal grant application, every five years, MCH is required to submit a Needs Assessment. Through the Needs Assessment, in addition to demographic data, public input is obtained from professionals, advocates and families to identify and rank needs and priorities.

In summary, the New Hampshire EHDI Program has the organizational structure, capacity and experience to continue providing excellent services to all infants born in New Hampshire and their families. The EHDI Program is well positioned to move forward in utilizing its data to monitor and improve identification of hearing loss and referral to appropriate and timely early intervention services for its youngest residents.