Introduction and Needs Assessment

Purpose of the Application

The Massachusetts Department of Public Health (MA DPH) is seeking funding through the U.S. Department of Health and Human Services, Health Resources & Services Administration (HRSA), Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs to enhance and improve upon the successful, comprehensive and coordinated statewide Early Hearing Detection and Intervention (EHDI) system of care and supports for families in the Commonwealth.

Description of the State/Territory EHDI System

In Massachusetts, the EHDI program is known as the Universal Newborn Hearing Screening Program (UNHSP). The UNHSP, which was created by legislation in 1998, is directed by Sarah Stone and resides within the Bureau of Family Health and Nutrition (BFHN), Division for Children and Youth with Special Health Needs (DCYSHN). The UNHSP Director reports to Elaine Gabovitch, the Director of the DCYSHN. Ms. Stone brings the perspective of a person with hearing loss to the program. Two UNHSP staff, Richard Wentworth and Jennifer Fleming, are parents of children who are deaf. Part C Early Intervention (EI) is organizationally located in the same bureau.

The project will focus efforts on engaging all EHDI system stakeholders at the state level to improve developmental outcomes of children who are deaf and hard of hearing, provide a coordinated infrastructure to ensure that newborns are screened by 1 month of age, diagnosed by 3 months of age and enrolled in EI by 6 months of age and reduce loss to follow-up/loss to documentation. The project will also identify ways to expand state capacity to support hearing screening in young children up to 3 years of age, strengthen capacity to provide family support and engage families with children who are deaf and hard of hearing and adults who are deaf and hard of hearing throughout the EHDI system. The project will engage, educate and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations; the need for hearing screening up to age 3, the benefits of a family-centered medical home and the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to families to facilitate the decision making process. It will facilitate improved coordination of care and services for children who are deaf and hard of hearing and their families through the development of mechanisms for formal communication, training, referrals and data sharing between the state EHDI Program and the Part C program.

The Massachusetts General Laws mandate hearing screenings for all hospital births, and directed the Department of Public Health to develop guidelines for screening at birth hospitals and pediatric audiology Diagnostic Centers. It also provided for insurance coverage of the screen and created an advisory committee with a mandated membership. The UNHS Advisory Committee, which includes not only the mandated membership but also members of many other stakeholder groups, has been meeting for close to 20 years to create and approve UNHSP policy. In addition to this group, the UNHSP has convened a larger stakeholder group that exists to share information and strengthen relationships within the broader community. Both groups include consumers, parents and professionals.

Babies born in Massachusetts receive a hearing screen prior to discharge from any of the 50 birth hospitals in the state. Babies who do not pass the screen (i.e., NHS refers) are scheduled for follow-up testing at one of 23 DPH-approved pediatric audiological Diagnostic Centers. This appointment is required to occur within three weeks of discharge. Information on the screening result and the appointment is entered by the hospital into the birth certificate, which is electronically linked to the child's record in the Massachusetts EHDI Information System (MA EHDI-IS)—a password-protected Microsoft Access database. The screening results of NHS referrals are retrieved from the MA EHDI-IS by the program's Lost to Follow Up Specialist, who contacts the family using a Department-provided cell phone to confirm that 1) the family understands the results, 2) that they know where and when the appointment is scheduled, 3) that they have transportation and care for older children, 4) that health insurance is in place, and 5) to review instructions for preparation for the diagnostic test. Appointment reminders are sent by text, and the primary care provider may be contacted to help reinforce messaging to the family.

The Diagnostic Center submits reports through secure email when babies complete or miss appointments. The reports are automatically uploaded into the child's record in the MA EHDI-IS. If an appointment is missed, additional follow up occurs with the family and primary care provider. Concerted efforts have been made by the Program Epidemiologist to improve audiological Diagnostic Center reporting. A fillable PDF was developed for completion by the diagnostic audiologist. The form includes demographic information on the child, including pediatrician information, risk indicators, types of testing completed and results achieved. Through Plan, Do, Study, Act cycles, the form was updated to reflect that the audiologist took the action of directly referring to Part C Early Intervention (EI). The audiologist also indicates whether the UNHSP-developed Parent Information Kit was provided, and if a referral was made to the Children's Specialists at the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH). The Parent Information Kit includes information specific to the Massachusetts EI system, as well as general information about hearing loss. The MCDHH specialists help families navigate services and are available to offer supports to the child through adulthood.

When a report documenting a hearing loss diagnosis is uploaded into the MA EHDI-IS, follow-up tasks are created by the Program Epidemiologist for UNHSP Outreach Specialists and the Special Projects Coordinator. The Outreach Specialist's task is to send a series of two letters to the family. The first is an introduction to the Family Outreach Specialist, notifying the family that they will receive a call from the Family Outreach Specialist, who is the parent of a deaf child. The Family Outreach Specialist's task is to make phone contact with the family to provide parent to parent support, review the Parent Information Kit, and discuss EI, specialty services, and the Family Sign Language Program. If the child has not already been referred to EI, the Family Outreach Specialist makes the referral. The Special Project Coordinator's task is to trigger the sending of a personalized letter on MA DPH letterhead to the deaf or hard of hearing (DHH) child's pediatrician from the MA AAP Chapter Champion. The letter outlines the potential effects of hearing loss, promotes EI, and enlists the pediatrician's help in fostering EI enrollment if enrollment is not confirmed by EI.

In Massachusetts, all infants and toddlers identified with a permanent hearing loss are eligible for EI services. These services are available at no direct cost to the family. The UNHSP has a memorandum of agreement with Part C EI, which is also located in the Department of Public Health's Division of Family Health and Nutrition. This agreement allows the UNHSP access to dates of referral and enrollment (the date of the signed Individualized Family Service Plan), as well as referral source, EI center, diagnosis, services received, exit date and exit reason. The UNHSP Epidemiologist matches EI data to UNHS data and enters the EI data manually into the EHDI-IS. A limitation of this system is that data is only provided quarterly, due to the time needed to create the data file.

If a child remains in process after the first examination, the date and location of the next appointment is entered into the MA EHDI-IS, and the Diagnostic Center is contacted if information is not submitted on that follow up appointment.

List of Stakeholders

- Families with children who are deaf or hard of hearing
- Consumers
- Birthing facilities (Program Directors, audiologists, screeners, birth certificate contacts)
- Midwives
- DPH Approved Audiological Diagnostic Centers, diagnostic audiologists and community audiologists
- Part C Early intervention staff, including the Director of Specialty Services
- Part C Early intervention providers (60 community programs in the state) and deaf and hard of hearing specialty service providers (9 community programs, 3 hospital based programs, and contracted individuals)
- EI Interagency Coordinating Council
- MA Chapter of the American Academy of Pediatrics
- Massachusetts Hospital Association
- Division for Children and Youth with Special Health Needs Director
- Director of Family Initiatives at the Department of Public Health
- Federation for Children with Special Needs, including the Family TIES program
- Universal Newborn Hearing Screening Advisory Committee
- MA Early Hearing Detection and Intervention Stakeholder Group
- Massachusetts Commission for the Deaf and Hard of Hearing
- Family Support Groups
- Private non-profits supporting services for deaf and hard of hearing children
- Home Visiting Programs, Title V (MCH and CYSHN), WIC
- DPH Office of Heath Equity
- Early Head Start, Head Start
- MassHealth (Medicaid)
- Leadership in Education and Neurodevelopmental Disabilities (LEND) programs (Boston Children's Hospital and UMass Medical Center)
- DPH Office of Birth Defects, New England Newborn Screening Program (blood screening)
- Department of Elementary and Secondary Education

Description of the Target Population

The UNHSP's target population includes all of the babies born in the Commonwealth that experience newborn hearing screening and their families. The 2017 Massachusetts birth data revealed that approximately one third of new mothers were unmarried, received WIC, and had government insurance as the primary health care payer, respectively (Table 1). The data also showed that about half of the mothers held bachelor's or advanced degrees, that 12.5% were black, and that the most prominent Hispanic/Latina group was Puerto Rican.

Table 1. Distribution of babies born in Massachusetts in 2017 according to sociodemographic factors

Factor	Number	Percentage
Total	71,439	100
Government Insurance	23,637	33.1
Family Received WIC	22,200	31.0
Mother Unmarried	23,718	33.2
Mother Has Bachelor's Degree	17,467	49.3
Mother Race White	50,911	71.3
Mother Race Black/African American	8,933	12.5
Mother Race Asian Indian	1,985	2.8
Mother Race Chinese	1,736	2.4
Mother Race Other Asian	2,409	3.4
Mother Race Other	5,354	7.5
Mother Hispanic/Latina	13,316	18.6
Mexican-American	501	0.7
Puerto Rican	4,665	6.4
Cuban-American	176	0.2

Overview of how the State/Territory is Performing with Regard to the 1-3-6 Recommendations

In 2017, Massachusetts had an overall screening rate of 99.5%. Of 560 babies that did not receive a hearing screen, 211 had died, 23 were not screened due to parent refusal, 126 were missed, and 200 had been born at home. The EHDI recommendation of screening by age 1 month was met by 98.9% of NHS passes and 93.8% of NHS referrals. Stays in Special Care or Neonatal Intensive Care Units (NICU) of nearly 20% of the NHS referrals may explain their longer time to screening, since screening occurs just prior to final hospital discharge. One in 8 (*n*=148) of the 1,212 NHS referrals were identified as DHH, and 129 (87.2%) fully met the EHDI follow-up recommendation by undergoing a diagnostic evaluation by age 3 months, and 114 (77.0%) received the DHH diagnosis by age 3 months. Normal hearing was found in 877 (72.4%) of the referrals; 807 (91.7%) fully met the EHDI follow-up recommendation, and 757 (86.3%) were discharged from further follow-up by age 3 months. Only 3.2% of babies that did not pass the screen were lost to follow-up for diagnostic evaluation. Of the 148 DHH babies among the

NHS referrals, 129 (87.2%) were referred to Part C EI services, and 85.8% became enrolled. However, only 60.1% of the DHH babies fully met the EHDI EI recommendation of EI enrollment by age 6 months.

Description of the Needs of the Population and Barriers to Receiving Hearing Screening and Intervention for Newborns, Infants, and Children and Up to Age 3 and Their Families

Barriers to NHS completion. Most voluntary Massachusetts home births do not receive NHS, and voluntary home births comprise over 60% of the babies for whom NHS is not documented. Midwives are not currently licensed in the state nor covered by NHS legislation, and there are no large practices of midwives, but rather a network of individuals. Midwives do perform blood screening, and information on the family's chosen midwife is available in the birth certificate. To date, the UNHSP has focused primarily on providing education to the families choosing home births. This has resulted in screening delays for these babies, or in the family's choosing not to pursue screening. Documenting the screenings of babies transferred to NICUs or other hospitals is always challenging, though a protocol exists for reporting such screenings.

Barriers to diagnosis. Infants who are identified as having normal hearing are identified by three months of age almost 90% of the time, but a delay does exist in achieving a diagnosis of hearing loss, typically caused by the family's having to return for a confirmatory diagnosis. Geographic isolation also contributes to not completing diagnosis. For example, NHS referrals born on Cape Cod, or on the islands off of Cape Cod, have to travel to an unfamiliar part of the state for diagnostic follow-up, and often they are unwilling or unable to do so.

Barriers to EI enrollment. Any delay in diagnosing hearing loss will necessarily be reflected in a delay in EI enrollment when the benchmark is stated in terms of age, rather than time between hearing loss diagnosis and EI enrollment. However, other factors also play a role in the failure to meet the EI timeliness recommendation. Specifically, analysis of UNHSP data collected since 2012 has identified mother's lack of a college education as a risk factor for not completing follow-up, as well as delayed hearing loss diagnosis and delayed EI enrollment once the diagnosis has been made (Table 2). Lower educational status could be a surrogate for barriers like lack of transportation or competing responsibilities such as work or care of other children. Perhaps supporting this view is a statistically significant 44% excess risk of not completing follow-up found with the 2017 data to be associated with being unmarried.

Audiologists' attitudes about direct EI referral have also stood in the way of achieving timely EI enrollment. Massachusetts audiologists have traditionally passed the responsibility for EI referral to pediatricians or social workers. One large Diagnostic Center's policy was for a social worker employed by the Diagnostic Center to make the referral, but only at an appointment subsequent to the one at which the hearing loss diagnosis was made. This policy introduced a delay that was often lengthened by barriers to keeping the appointment such as illness, weather and the like.

Barriers to documenting hearing testing of children up to age 3. Currently, efforts to provide screening to children outside of the newborn period are fragmented. Early intervention programs recommend hearing screening for certain children receiving services from them. Early Head Start and Head Start provide hearing screenings within their practice. Results are provided to primary care providers, but are not currently collected statewide. Collaborations will be sought with early childhood programs to share best practices and determine systems of data documentation.

Description of Disparities Based on Race, Ethnicity, Gender Identity, Sexual Orientation, Geography, Socio-economic Status, Disability Status, Primary Language, Health Literacy, and Other Relevant Dimensions

The associations between mother's lack of a college degree and incomplete follow-up, delayed hearing loss diagnosis, and delayed EI enrollment of DHH children, could reflect the effect of poor health literacy. Alternatively, the disparities might be more directly connected to poverty. Supporting this idea were significant associations found with the 2017 data between paying for health services by any method other than private insurance and failing to complete follow-up. Independently of education, UNHSP data collected since 2012 identified maternal non-Hispanic black race as a risk factor for failing to achieve a hearing loss diagnosis by age 3 months. Also independently of lower maternal education, not receiving a diagnosis at all was positively related to maternal Hispanic white race, maternal non-Hispanic black race, and residence outside of the Metrowest and Northeastern regions of the state. Completing follow-up was particularly unlikely in the Western region, which, along with the Southeast region, is underserved by pediatric audiologists. Racial/ethnic disparity was particularly apparent in the percentages of DHH babies achieving timely EI enrollment. DHH babies whose mothers were black, Asian, or Hispanic achieved timely EI enrollment much less frequently than DHH babies of non-Hispanic white mothers.

Not only were children of non-Hispanic black and Asian mothers less likely than children of non-Hispanic white mothers to fully accomplish the EHDI 1-3-6 goals, they were also more likely to be diagnosed with hearing loss when they did follow up. This association reinforces the importance of improving follow through for these population subgroups. The excess risk of hearing loss did not apply to all Asians equally. Babies of Cambodian and Japanese women were 1.5 to 2 times as likely as babies of mothers of other Asian ethnicities to be diagnosed with hearing loss, but babies of mothers who were Asian Indian, Chinese, Vietnamese, or Korean did not appear to be at elevated risk.

Among 7,632 babies who referred on NHS between 2012 and 2017, 13% identified their preferred language for reading or speaking as something other than English. That factor, *per se*, was not found in data analyses to be related to follow-up completion or the timeliness recommendations. However, the low likelihood of completing follow-up by NHS referrals residing in the Southeastern part of the state appeared to be exacerbated by a preference for a language other than English. Specifically, while 66% of NHS referrals born to English-speaking mothers residing in the Southeast region completed follow-up, only 53% of NHS referrals born to non-English speakers in that part of the state did so—a significant difference. Babies born to non-English speakers were also more likely than English speakers to be diagnosed with hearing loss.

Table 2. Relationships[1] between Education, Race/Ethnicity, Primary Language, and Geography and Follow-Up Completion, Timely Hearing Loss Diagnosis, Timely EI Enrollment, and Hearing Loss among Babies Born in Massachusetts (2012–2017)

Factor	Follow-Up Completion of NHS Referrals	Timely DHH Diagnosis of NHS Referrals	Timely EI Enrollment (DHH)	Hearing Loss Diagnosis (per 1,000 births)
College Degree				
No	63%*	61%*	63%*	2.9*
Yes	73%	72%	78%	2.5
Race/Ethnicity				
H-White	64%*	61%	64%*	2.8
H-Black	68%	68%	62%	2.5
Asian	67%	73%	61%*	3.1*
NH-Black	65%*	50%*	60%*	3.1*
Other	69%	75%	75%	2.1
NH-white	69%	70%	76%	2.5
English Speaking				
No	67%	63%	66%	3.7*
Yes	67%	67%	71%	2.5
Mass. Region of Residence				
Western	48%*	67%	65%	2.0*
Central	68%*	71%	71%	2.7
Northeast	72%	64%	77%	2.8
Southeast	65%*	65%	76%	2.6
Boston	69%*	63%	61%	2.8
Metrowest	74%	70%	70%	2.6

***Statistically significant difference between the designated category and the last (referent) category listed in the series.**

Methodology, Work Plan, and Resolution of Changes

A. Description of Efforts to engage all stakeholders in the State/Territory EHDI System to improve developmental outcomes for children who are DHH

1. Plan to provide a coordinated infrastructure to a) ensure that all newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI by 6 months of age (1-3-6 recommendations); and b) reduce loss to follow-up/loss to documentation.

Screening by 1 month of age. Through a coordinated infrastructure of birth registrars, NHS Program Directors and screeners at 50 birth hospitals, as well as UNHSP staff comprising an Outreach Specialist, a Lost to Follow Up Specialist, and an epidemiologist, the UNHSP consistently achieves a 99.5% documented screening rate. This is accomplished, in part, through a linked database that matches records in the EHDI-IS to electronic birth certificates, into which the hospital birth registrars enter screening results, screening date, and follow-up appointment information. This reporting system is augmented by a protocol for faxing to the UNHSP the same information for transferred babies, whose birth certificates are not available to their screening hospitals for direct data entry. The UNHSP's current timely screening rate of 98.3% is well above 95%. Therefore, by March 2024, we will increase by 1% from a baseline of 70,039 the number of infants that completed a newborn hearing screening no later than 1 month of age, to a final total of 70,739. The UNHSP's greatest, correctable screening challenge relates to the home birth population. In this project, the UNHSP proposes to address this challenge by providing information about screening to the midwives, rather than to parents, in an effort to streamline the process by which families choosing home births are able to secure a hearing screen. The UNHSP will engage a midwife and our Chapter Champion in midwife-educating initiatives aimed at increasing midwife investment in early hearing loss detection.

Some babies born in hospitals miss their screens, and for some babies screened in hospitals, documentation of screening is never received by the UNHSP. Although no subgroup of unscreened babies who survived to be screened in 2017 was nearly as large as the home births (*n*=200), transferred babies comprised the next largest group (*n*=78). A major barrier to completely documenting the screenings of transferred babies is lack of understanding by new screening staff of the unique reporting protocol created for these babies and the reason for it—particularly when the child has only been transferred to the NICU in the same hospital. The usual reason for the special protocol is that only a child's birth hospital has access to his/her birth certificate for screening-data entry. However, if screening is delayed by a NICU stay, the birth certificate may be closed before screening results are available. Two specific hospitals were responsible for the large proportion of 2017 births transferred to the birth hospitals' NICU and whose screenings were never documented. Both hospitals have new NHS Program Directors, and the UNHSP epidemiologist will collaborate with the new people on an improved reporting system for NICU transfers.

Diagnosis by 3 months of age. The percentage of 2017 NHS referralss who had completed a diagnostic audiological evaluation by age 3 months was 82.0%. For babies diagnosed with normal hearing, the percentage was 92%; whereas, for babies diagnosed with hearing loss, it was 88%. Consequently, the departure from the benchmark of 85% was mainly due to babies who had no documented follow-up at all. By March 2024, the UNHSP will ensure that the percentage who had completed a diagnostic evaluation by age 3 months is 85% by addressing loss to follow-up as outlined in the relevant section below.

The 2017 UNHSP data reveal that a diagnosis of hearing loss took longer to achieve than a diagnosis of normal hearing. Specifically, according to the 2017 data, median time from birth to diagnosis was 35 days for babies diagnosed with normal hearing and 56 days for babies diagnosed with hearing loss. Though one might speculate that babies eventually diagnosed with hearing loss would be more likely to have been born prematurely, data analysis did not bear that idea out in that the mean gestational age of both groups was 38 weeks. The longer time to diagnosis observed in babies eventually diagnosed with hearing loss is likely related to the audiologists' practice of bringing the child back to confirm the diagnosis and reporting to the UNHSP that hearing status could not be determined at the first visit when hearing loss was actually diagnosed. This has been confirmed through comparisons between reports received by the UNHSP and those sent to pediatricians. The calculated time to diagnosis is likely further lengthened when the confirmation appointment is put off due to illness, competing appointments, etc. During the funding period, UNHSP leadership will work with the reporting audiologists to foster more accurate reporting. Sometimes the first or only follow-up appointment occurs later than expected due to lack of availability of audiologists qualified to evaluate very young children. To address this barrier, the UNHSP will continue to try to encourage audiology and ENT practices to apply to become approved Diagnostic Centers, particularly in the underserved areas of the state.

EI enrollment by 6 months of age. Because all out-of-pocket costs for EI in Massachusetts were removed in 2012, the state's overall EI-enrollment rate has been close to 90% in recent years, and some of the small group not enrolled in Massachusetts resided out of state or were too ill to participate. Enrollment was not always timely, however, with only around 60% of children diagnosed with hearing loss becoming enrolled by age 6 months. By March 2024, the UNHSP will have increased this percentage to 80% by a combination of initiatives including those begun recently to address this deficiency and those planned for the funding period. The already instituted practices include the sending of 2 EI-related letters to the parents of DHH children as soon as the DHH diagnosis is reported and the timely notification of the DHH child's pediatrician of the child's EI eligibility based on the DHH diagnosis. UNHSP leadership has also been effective at changing the behavior of audiologists at one large Diagnostic Center by explaining the potential consequences for DHH children of requiring a separate appointment for EI referral. The report card sent to the Diagnostic Center Directors was also recently revised to include information about the timeliness of EI enrollment of children diagnosed with hearing loss at the center. As noted in the previous paragraph, encouraging immediate reporting of the DHH diagnosis rather than waiting for results of a second evaluation using the same tests is also expected to shorten the time to EI enrollment. Audiologists who never make direct referrals can be identified with the checkbox for indicating direct EI referral that was added to the revised diagnostic evaluation. During the funding period, these audiologists will be targeted for further attempts to promote direct EI referral.

Reduction of loss to follow-up/loss to documentation. Loss to follow-up/loss to documentation is an ongoing challenge. The UNHSP has met this challenge and achieved a 3.2% lost-to-follow-up rate by instituting various measures to facilitate follow up and tracking of NHS referrals. These measures include addition to the Massachusetts birth certificate of fields for recording appointment location and date of the first follow-up appointment, creation of a staff position dedicated to reducing loss to follow-up, hiring a bilingual (English/Spanish) person as the Lost to Follow-Up Specialist, paying for the Language Line to communicate with parents who speak languages other than English or Spanish, institution of a protocol for notification and follow up after a missed diagnostic evaluation appointment, addition to the diagnostic evaluation form of a field for recording the date of the next appointment for patients whose follow-up has not been completed, follow up with Diagnostic Center Directors on undocumented completed evaluations, and establishment of the Department of Public Health as the payer of last resort for the first diagnostic test for NHS refers. These measures will continue throughout the funding period to maintain the UNHSP's low lost-to-follow-up rate. UNHSP leadership will also continue to educate staff of birth hospitals and audiological Diagnostic Centers on the importance of timely data reporting, including missed appointments.

2. Plan to expand infrastructure, including data collection and reporting, for hearing screening for children up to age 3 by the end of year 2. In year one, the UNHSP will partner with Part C Early Intervention to provide education to service providers regarding the recommendation of audiological testing for children enrolled in early intervention for speech delays as well as other risk indicators.

The UNHSP has provided guidance to birth hospitals on risk indicators, and birth hospitals are required to make appointments for babies that passed their hearing screening, but have certain risks including CMV, bacterial meningitis, Down syndrome and others at 3 months of age. Furthermore, the Electronic Birth Certificate (EBC) was recently revised to allow appointment information for babies that passed their hearing screen to be entered. Previously, those fields were only available for NHS referrals. This change will allow the UNHSP to more closely track children with certain risk indicators and provide education to families and providers around additional evaluations required.

For children with risk factors for hearing loss and/or when provider or parental concern has been voiced, a streamlined testing process is imperative. In efforts to increase the percentage of babies screened by one month of age, support from our midwife community has been enlisted. In addition to working with messaging for families and clarification on screening and testing needs, a clearly defined contact list and process by location will be generated. In this manner, babies born outside of the hospital will have a clear path to screening and testing. This will be important for children with risk factors for hearing loss as well. Information will be communicated to families and will be accessible on the UNHSP website to assure appropriate, timely, and effective screening and testing takes place.

By the end of year 2, a state plan will be developed to expand infrastructure, including data collection and reporting, for hearing screening for children up to age 3. This will include resources, key stakeholders, partnerships and services necessary to implement the plan. The UNHSP is a program within the Massachusetts Department of Public Health's Division for Children and Youth with Special Health Needs (CYSHN). CYSHN, the Division of Early Intervention, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and the Pregnancy, Infancy, and Early Life Division, which houses Prenatal and Early Childhood Home Visiting Programs, are all under the umbrella of the Bureau of Family Health and Nutrition. This existing infrastructure will ensure a public health approach that aligns with other public health and/or service programs within the state.

The UNHSP will partner with the Early Childhood Hearing Outreach (ECHO) Initiative, which has successfully trained staff from many Early Head Start programs, with the hope of adopting their methods to engage Early Head Start programs in the effort to expand identification of children with hearing loss up to age 3.

3. **Plan to establish and maintain partnerships for referral, training, and information sharing with various state or territory stakeholder organizations and programs that include, but are not limited to, health professionals, service providers, birthing centers, and state or territory organizations and programs.** The UNHSP's current partners include 50 birth hospitals, 39 audiological Diagnostic Centers approved by the state to perform hearing testing on children, the Division of Early Intervention, the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), 3 companies that provide newborn hearing screening at certain Massachusetts birth hospitals, the EHDI Coordinators of the other 5 New England states, the

UNHS Advisory Committee and the members of a Stakeholder Group comprised of a wide range of consumers and professionals that supports families with DHH children and was modeled after the Stakeholder discussions at the EHDI meetings.

Written guidelines for both testing and reporting have been prepared for the hospital NHS programs and the state-approved Diagnostic Centers. Twice yearly, UNHSP leadership meet face-to-face with representatives of the Diagnostic Centers to reinforce, among other purposes, certain guidelines or convey the need for changes. A third annual meeting of this group is an educational webinar, to which families are also invited. Topics have included, among many others, atresia/microtia, DHH children with autism, dual language learners, and findings from the Outcomes of Children with Hearing Loss Study.

Massachusetts has taken the lead in convening a group of New England EHDI Coordinators in monthly discussions that includes quality improvement initiatives, family initiatives and discussion of challenges and opportunities facing EHDI programs. One notable accomplishment of this group was the development of a data-sharing agreement to allow screening data to be shared among the New England states on transferred babies.

UNHSP staff participates in the Deaf and Hard of Hearing Early Education Task Force, which is convened jointly by the MCDHH and the Department of Elementary and Secondary Education. The Task Force is currently working on a document to assist families in the transition from early intervention to school based services. A group of Specialty Service providers under the leadership of the Director of EI Specialty Services planned and implemented a Specialty Service Summit for EI providers, many of whom were not aware of the 1-3-6 guidelines—the topic discussed by Dr. Christy Yoshinaga-Itano in a UNHSP-funded presentation. Another summit will be held next year.

By the end of year 1, and annually thereafter, the UNHSP will complete an assessment of current partnerships. Key partners to address gaps in the EHDI system will also be identified. For example, pediatric ENT practices, which perform hearing testing and would likely have test results for children up to age 3, are not currently involved in the UNHSP reporting network. Expanding the UNHSP testing/reporting network to include ENT practices should facilitate documentation of hearing testing of children up to age 3.

4. Description of the membership and meeting schedule of the Massachusetts EHDI Advisory Committee. The MA UNHSP has a long standing Advisory Committee, whose official membership is included in legislation. The fourteen members include two parents of DHH children, one deaf and one hard of hearing adult designated by the MCDHH, one neonatologist, one representative of the Commonwealth's EI program, one representative of the department of public health, two audiologists, one teacher of the deaf and hard of hearing, one otolaryngologist, one pediatrician or family practitioner, one nurse representing newborn nurseries, and one representative of the health insurance industry. Currently, only 12 of the 14 slots on the committee are filled. It has been challenging to maintain an active nursing member and an active health insurance industry member since the legislation was originally passed and the regulations were written for the birthing facilities. The Committee is chaired by a parent of a child who is deaf. Of the 12 currently appointed members, five members are either parents or consumers, exceeding the 25% minimum. Meetings of this body are public, and many other stakeholders attend, including the CYSHN Director and representatives of schools for the deaf, the MCDHH, and DPH Office of Health Equity. The Advisory Committee meets twice annually and advises the UNHSP on policies. Data presentations are frequent. Past topics include inclusion of Deaf adults in research, risk indicators, Cytomegalovirus (CMV), changes in the provision of EI services, and Usher Syndrome.

5. Plan to address diversity and inclusion in the EHDI system to ensure that the Massachusetts EHDI system activities are inclusive of and address the needs of the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status. By the end of year 2, the UNHSP will develop a plan to address diversity and inclusion in the EHDI system to ensure that the state EHDI system activities are inclusive of and address the needs of the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure and socio-economic status. This includes the identification and development of parent leaders that are representative of the entire population served.

Racial equity is a priority of the Department, and Bureau Director Dr. Craig Andrade is one of the founding members of this initiative. Reaching the less reached and raising all families' stories are two of the Bureau's racial equity priorities. UNHSP staff have completed a 2 day racial equity training in addition to other diversity trainings at the Department.

The Division for Children and Youth with Special Health Needs is currently undergoing a 5-year strategic planning process, and examining programs with a racial equity lens will be a strategy moving forward. The Division is also leading the way to ensuring that disability is also considered as a part of achieving equity. Data have been analyzed and will continue to be examined to determine inequities in receiving a timely diagnosis and timely EI enrollment. Disparities have been found based on geography, and the UNHSP has made efforts to increase the number of audiological Diagnostic Centers in underserved regions of the state. In December 2019, the UNHSP epidemiologist will make a presentation on racial ethnic disparity in hearing loss detection at the annual Department-wide epidemiology conference.

Events for families are held in geographically diverse areas of the state, and all efforts are made to ensure that locations are accessible by public transportation and that accommodations are available. ASL and other language interpreters are secured. Materials for general audiences are translated into 13 languages, as informed by birth certificate data. Materials for families with DHH children are currently available in English and Spanish. Data indicate that 197 of the 217 families with DHH children read either English or Spanish. Haitian Creole and Portuguese are read by 9 and 3 families, respectively. Other languages were represented by singular families. UNHSP staff have capacity in English and Spanish, and a language line or relay is utilized for all other languages, which last year included Portuguese, Mandarin, Haitian Creole and French.

Accessibility standards are followed for all materials posted on the UNHSP website, including open captioning. Materials are provided in multiple formats and are accessible to screen readers.

Not only will all of these initiatives be continued over the course of the funding period, but new means will also be sought to ensure that the Massachusetts EHDI system activities are inclusive of, and address the needs of, the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.

6. Plan to develop and implement a strategy to monitor and assess program performance. Project management tools will be employed to ensure adherence to the work plan. When indicated, pre- and post-testing will be completed as well as satisfaction surveys from participants. Feedback on needs will be sought from parents through established committees as well as through a survey distributed through email and through social media. Quality improvement methods will be integrated into the project including Plan, Do, Study, Act cycles and process flow will be examined. Additional training will be sought on using specific tools like Visio. The UNHSP will collaborate with the EHDI National Technical Resource Center in quality improvement activities and others described in the UNHSP work plan.

The UNHSP will focus on 2 areas of improvement: EI enrollment and provider outreach and education. Existing gaps and challenges will be identified. Goals, methods, and timelines for improvement will be developed and stakeholders named.

Early Intervention services are voluntary and require a time commitment from families, often resulting in families having to make adjustments to work schedules. Services in Massachusetts are provided at no cost to families and are available to children with any level of permanent hearing loss, regardless of laterality. However, if the message provided to the family is that services don’t need to begin until there is a delay, the level of urgency is lost and enrollment into early intervention might not occur until after age 2. Messaging from providers needs to be clear and consistent. Providers include audiologists, primary care providers and early interventionists. These families may also not be offered additional services from specialty service providers, who understand best how hearing loss affects language development. EI enrollment by diagnostic center data will be investigated as will group pediatrician practice data. Goals, methods, timelines for improvement will be developed and stakeholders named.

7. Plan to develop, maintain, and promote a website or webpage for Massachusetts that is user friendly with accessible, culturally appropriate information for families and professionals that is accurate, comprehensive, up-to-date, and evidence-based, as appropriate to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communication modalities, as appropriate. In the past several years, the platform for the Commonwealth’s webpages was updated. All program pages underwent a review and remodel. Features have continued to be added to the website, and the UNHSP has fully participated in these efforts to keep our pages informative and streamlined. The website is maintained by the Commonwealth’s Web Team and processes are in place at the Bureau level to review and approve materials. The Commonwealth has accessibility guidelines, and all posted material must conform to those standards.

The webpage is located at https://www.mass.gov/universal-newborn-hearing-screening-program. Information found in our Parent Information Kit including recommendations for early parent-to-parent support is available. Links are provided to the Department’s Hearing Aid Program as well as the Family Sign Language Program and other Department resources. Links are provided to outside organizations including HRSA, CDC, the National Center for Hearing Assessment and Management, Hands & Voices, Boys Town National Research Hospital, and Massachusetts specific organizations. The learning community in the previous funding cycle was crucial in adapting pages to better suit professional audiences and content will be reorganized based on their recommendations. The site will be restructured based on individual seeking information. Sections will be organized by parents/families, primary care providers, early interventionists and audiologists. The content will be tailored to meet the individual needs of the parents and professionals who support them. The family perspective will be consistent and included throughout provider sections. Additional content will be added to make the site more robust for professionals served. UNHSP will continuously edit and update the website as new information becomes available. The learning community will provide feedback after changes are implemented for further refinement. This multidisciplinary team will assist in expanding the breadth of information and the reach of this tool to educate and inform professionals and families as they support children who are deaf and hard of hearing throughout the Commonwealth. Information on laws, regulations and guidelines are available. Links are also provided to the Joint Committee on Infant Hearing statements, current research and resources to help providers assist families. The UNHSP promotes its website to families through brochures provided to families at the time of screening, the Parent Information Kit provided to all families at the time of identification, and to professionals through presentations and materials.

The UNHSP also has an active Facebook page https://www.facebook.com/MassNewbornHearingScreening/ enabling the program to reach a wider audience in the promotion of events and activities for families and professionals. It also allows a range of materials to be accessed, including news articles and related stories of interest.

8. Description of the plan for project sustainability after the period of federal funding ends. The UNHSP currently receives funding from four sources: HRSA, CDC, MCH Block Grant and the state. Once the period of federal funding ends, key elements of the program will continue. Hearing screening is mandated by law and included as a requirement for hospitals in the birth hospital licensure guidelines. Reporting of screening results, follow-up appointment information, demographic information, and medical risk information is provided in the electronic birth certificate. Audiological Diagnostic Centers are approved by the Department using established guidelines, and appropriate pediatric testing will continue to be provided after the funding period ends. Families with DHH children are automatically eligible for EI services.

The EHDI-IS is managed by internal IT staff. Secure email is provided by the Department. The website is maintained by the Commonwealth. The Advisory Committee is mandated by statute. Through the Advisory Committee, the medical community has provided technical support and assistance in developing policies and participating in training at no direct cost to the program. MCH Block Grant funds would continue to be utilized to maintain parent involvement and provide parent to parent support, as family engagement is a cornerstone of our Division's priorities. The small amount of state funding would allow for outreach to families and pediatricians. Additional funding would be sought to maintain the high levels of excellence that is expected of the UNHSP.

B. Engage, Educate, and Train Health Professionals and Service Providers in the EHDI system.

1/2. Plan for conducting outreach and education to health professionals and service providers in the EHDI system. The UNHSP will 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 in year 1. Pediatricians, EI providers, and specialty service providers will be the primary focus of the outreach and education.

The UNHSP has partnered with the AAP Chapter Champion to educate primary care providers on the importance of timely screening, diagnosis, referral and enrollment into EI services. Pediatrician contact information is provided in the electronic birth certificate, and information is sent to the pediatrician to assist in achieving the 1-3-6 goals. Large pediatric practices with multiple DHH children will be identified, and in-person training will be provided by a physician/parent team. Materials on risk indicators and required follow up will be provided through the AAP's publication, The Forum. Website materials will continue to be refined, including materials for primary care providers.

In the work of the Learning Community, the UNHSP partnered with the Department's web team to gain a better understanding of how the website was being used. Through their on-line survey questions, it was determined that the website is primarily accessed by professionals to obtain guidance documents, process flows and information to provide to families upon diagnosis. Providing complete and easy to access information on the website will continue to be a priority under this funding.

The UNHSP will partner with the Division of Early Intervention's Office of Specialty Service to provide information to professionals working with families in EI. There are 60 EI providers in the state. Each provider has an identified point person for DHH information. This individual is not necessarily on the team for every DHH child, but rather supports staff having these children on their caseload. This provides a central point of contact and allows for streamlined information distribution.

Surveys will be provided to the DHH contacts at EI programs to obtain a baseline, and interventions will be planned based on those results. The interventions will include, but not be limited to, a presentation at an annual meeting, an exhibition at the Massachusetts EI Consortium Conference, and provision of materials for inclusion in the EI newsletter and emails.

Although specialty service providers are all well versed in providing services for DHH children and understand the urgency in receiving early supports, they are not always well versed in what the EHDI 1-3-6 goals actually mean. Specifically, they may not fully understand the steps involved in accomplishing the 1-3-6 goals. In-person training will be provided to leaders at the specialty service programs and pre- and post-testing will be completed.

Presentations will be made to LEND programs, and current LEND fellows will be invited to participate in UNHSP meetings and activities.

C. Description of Strategies to Strengthen the Capacity to Provide Family Support and Engage Families with Children who are DHH as well as Adults who are DHH throughout the EHDI System.

1.Plan to engage families in the EHDI Program. The UNHSP will 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 in year one.

Family engagement is a core value of the Division for Children and Youth with Special Health Needs, and the following definition was developed and adopted by Division staff: "Family Engagement is the intentional practice of partnering with families to support positive outcomes in their lives and to improve and enhance our work by actively developing ways for families to share their lived experience and expertise. Family Engagement is based on the belief in the importance of family involvement and leadership at the individual, community and systems level and is infused with the DCYSHN core values."

Family-to-family support services are provided in many ways in Massachusetts. Family TIES, a program funded by the Massachusetts Department of Public Health and operated by the Federation for Children with Special Needs, a family led organization, provides information and referrals to families. They train parents to become support parents and are matched with other families. Connections are made by phone. The UNHSP has encouraged families to become trained support parents and included the Federation's support parent training in last year's Parent Forum, a day of education and information for families. The UNHSP will continue its contract with the Federation for Children with Special Needs and draw on their expertise and programming.

Families are engaged at all levels in the UNHSP. Currently, two paid part-time staff positions are held by parents; two formally appointed parents are members of the Advisory Committee, and a parent chairs the committee. Agendas for the Advisory Committee meetings are set collaboratively by the Committee Chair and the UNHSP Director. Parents participate in, and are frequent presenters at, the Stakeholder and CMV meetings. Stipends are provided to all parents who participate in these activities. Family social events are held for families across the state, and an annual Parent Forum is planned by parents in conjunction with UNHSP staff. Input into location for activities and topics for conversation are sought from families. Whenever possible, parents are paired with professionals to deliver presentations.

The UNHSP strongly believes in meeting families "where they are at" and provides opportunities for varying degrees of participation and commitment. Family-to-family support is provided by UNHSP's Family Outreach Specialist, who is a parent of a DHH child. Upon the receipt of diagnostic information, contact is made with the family to provide unbiased information, assist in enrollment into early intervention and to provide support to the family early on. Families are encouraged to maintain contact, and requests are made to share email addresses. Those addresses are added to a distribution list maintained by the UNHSP. Frequent messages are sent regarding upcoming opportunities to meet other families, conferences, other learning opportunities and information that may be helpful to families. The Family Outreach Specialist and the Special Projects Coordinator (also a parent of a DHH child) assist in the creation and execution of all UNHSP social and educational events. These informal gatherings provide parents the opportunity to learn from other parents and for the children to interact with other children who may not utilize the same communication modality. The UNHSP constantly seeks to identify parents of younger children who may be interested in becoming more involved in the EHDI program. UNHSP hosts an active Facebook page www.facebook.com/MassNewbornHearingScreening which provides families another way to interact with the program and each other.

DHH mentorship is an important component to providing family support. The UNHSP has found that families with young children are seeking out opportunities to meet older children as well as adults. Representation of all levels and types of hearing loss including unilateral losses is crucial. This topic was explored at a Stakeholder Meeting with a representative from Partners for Youth with Disabilities (PYD) mentoring program, and models were described with other disabilities including a partnership PYD has with the Massachusetts Commission for the Blind.

The UNHSP will increase by 10 percent 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 in year 1. Currently DHH adult-to-family services are available through specialty providers in early intervention programs, the Family Sign Language Program (a program funded through Early Intervention that provides instruction to families in ASL by a Deaf adult), the Shared Reading Program (a program designed to teach parents and caregivers how to read to their children who are deaf and hard of hearing using American Sign Language with Spanish and English interpretation throughout), Partners for Youth with Disabilities and through social events hosted by UNHSP. There is no single entry or data point. In this grant, the UNHSP proposes to contract with Margaret Lee, a DHH adult who utilizes hearing aids and is a fluent signer, to explore models for providing DHH adult-to-family support services. Ms. Lee has worked as a Children's Specialist for the MA Commission for the Deaf and Hard of Hearing and has extensive experience in early intervention in the New England region. She will review current services and explore models utilized in other states. A recommendation will be made at the end of year 1 for implementation, and additional funding sources will be explored.

Groups are also run by Specialty Service Providers within EI. Although not provided by a family-led organization, according to parents, these groups are a valuable source of information. There are also support groups run by audiologists within the state that have a very active membership. National organizations, such as AG Bell, support training and family activities throughout the year. The Decibels Foundation was founded in 2002 by two families of children with hearing loss. The mission of the Decibels Foundation is to help children with hearing loss and their families. They manage an active list of family events throughout the Commonwealth. The UNHSP shares this calendar of family events on our website. Links to additional family resources will be further developed as our website improvement efforts continue.

The UNHSP will increase by 20 percent the number of families enrolled in family to family support services by no later than 6 months of age. Data collection methods will be determined to limit duplication of data. Aggregate data are available from Family TIES, and the UNHSP will work with the program to determine methods to better drill down to those families with DHH children. Currently 27 support parents have been trained by Family TIES. Seventeen have a child with a primary diagnosis of hearing loss. Seven have a secondary diagnosis of hearing loss. Three are Deaf-Blind. Five parents of DHH children requested matches. One match was complete. Three were closed before a match was made. The UNHSP will work collaboratively with Family TIES to increase numbers of parents trained and matches made.

During the funding period, parent partners will participate in the evaluation to measure the effectiveness of family engagement activities. The UNHSP will continue to work with the Federation for Children with Special Needs and the Office of Family Initiatives to engage diverse families to ensure representation of race, geography, language, socio-economic status and disability. Consultation will be sought from the Family Leadership in Language and Learning Center (FL3) to strengthen the infrastructure and capacity for family engagement and family support. Additional collection of parent email addresses will be explored, as families report email communication is preferable to voice messages.

2. Plan to conduct outreach and education to inform families about opportunities to be involved in the EHDI system. The UNHSP recognizes that families have other commitments and may not be able to attend meetings or events during the typical work day. The UNHSP also recognizes that family time needs to be respected. Advisory Committee meetings are held in the late afternoon, and events for families are held on weekends and holidays and include the whole family. Feedback is sought from families electronically when possible.

The UNHSP has provided funding to parents to attend the EHDI meeting, statewide conferences and other training opportunities. The UNHSP continues to encourage parents to become support parents through Family TIES (together in enhancing support). The program then matches parents with other parents to provide support over the phone. Training is provided by the Federation for Children with Special Needs, funded by the Department of Public Health. These training efforts are ongoing, and a special training session was offered to families with children who are deaf and hard of hearing at last year's Parent Forum.

The Office of Family Initiatives at the Department of Public Health also provides leadership training to families. The Family Leadership Training Institute was created for families who want, and are ready, to learn leadership skills that will assist them in making enhancements and changes across the system of care. The program has changed in scope and delivery based on continuous improvement measures, funding and needs of parents and families. Participants learn about, among other things, the history of the disability movement to include the role Gallaudet played in the passing of the Americans with Disabilities Act, how to work on teams, conflict resolution, how the legislative process works and how to use it make change. A number of parents of DHH children have participated in this training program and have gone on to support EHDI, EI, and parent support and education in the state of MA.

The Early Intervention Parent Leadership Project (EIPLP) in the Office of Family Initiatives works to develop family leaders within the EI system. Staff are parents of children that received EI services and are experienced in identifying prospective families and providing coaching and mentorship. The UNHSP will collaborate with the EIPLP to expand methods of identifying future leaders and providing adequate training to strengthen their relationship with the EHDI system.

Opportunities will also continue to be presented to families through email, Facebook, the UNHSP website, EI providers, specialty service providers, audiologists, schools, and UNHSP-hosted events.

3. Plan to facilitate partnerships among families, health care professionals, and service providers to ensure that providers understand the best strategies to engage families. The UNHSP will continue to expand its partnerships to positively affect services for families. In this past grant cycle, much work was done with EI and with Specialty Services in particular. The UNHSP works closely with the Director of Specialty Services and is on the planning committee for an Annual Summit for EI providers specifically regarding hearing and vision loss. These low-incidence conditions are not commonly occurring in the EI population, and the group is working to develop and distribute guidance for those EI service coordinators in the field who may not have ever had a DHH child on their caseload. Sixty agencies provide EI services in Massachusetts, and constant education is needed as staff turnover is high. Education is also necessary for Program Directors to ensure that billing policies and other administrative tasks are clear. An example of a policy is, unlimited co-visits are allowed between service coordinators and DHH specialty service providers. This allows service coordinators to learn from experts in DHH children. However, if the billing policy is not understood by the agency, this practice does not occur. The UNHSP can play an important role in providing education to EI providers and bringing service providers together. The UNHSP will exhibit at the annual EI conference and provide information and education to attendees.

The UNHSP developed a one-page document titled “From the Roots Up: A Family’s Journey Through Deaf and Hard of Hearing Services.” This document was based on the idea of a care map and was done in conjunction with the Learning Community in the last grant cycle. This document pulls together information on what services the family may engage with from infancy up to school age. The primary audience is families, but secondary audiences include pediatricians, early interventionists, and audiologists. The document is distributed in the UNHSP Parent Information Kit, is included in all mailings to primary care providers, and has been provided to the deaf and hard of hearing contacts in each early intervention agency. Feedback from families and professionals alike has been extremely positive. This tool was presented to families and colleagues at the last EHDI national meeting and was positively received. Strategies to further disseminate this tool to improve family/professional partnerships will be investigated. This resource will be made available in multiple languages.

The UNHSP recognizes that audiologists and primary care providers have a unique opportunity to facilitate EI enrollment, and continuous education around the enrollment process is provided. Audiologists are asked to refer families to EI directly, even if the diagnosis is not confirmed, but a permanent loss is suspected. Children with confirmed permanent hearing loss are automatically eligible for EI in MA until the age of 3 (regardless of laterality). If permanent hearing loss is suspected, but not yet confirmed, the process of EI enrollment can still begin, and the child will be enrolled under ‘clinical judgement’ with a re-evaluation done in 6 months. Audiological workup is expected to be completed within that time. The UNHSP continues to educate audiologists about this policy, as well as to encourage families to request services provided by a DHH specialist. The more informed audiologists are about EI, the more supports they can provide to families. The UNHSP will provide at least one statewide training on EI processes and expectations.

Primary care providers are engaged by UNHSP at several points. Providers are notified if a baby did not pass the screen and missed his or her follow up appointment. A letter from the EHDI American Academy of Pediatrics Chapter Champion is sent to all primary care providers who have a DHH child in their practice who is not enrolled in EI. This letter is on Department of Public Health letterhead, and is signed by the Chapter Champion in her capacity as a member of the UNHS Advisory Committee. Letters are generated by UNHSP staff and information including the one-page “From the Roots Up” document is included. Each letter is tailored towards the patient and physician and stresses the importance of early supports and services. Phone outreach to pediatricians and practices will also be utilized to follow-up on children where appropriate. In person visits may occur in conjunction with primary care training sessions to be scheduled at group practices. The outcome of this partnership with the AAP Chapter Champion will be evaluated and adjustments made to better serve children and families.

The previously described Stakeholder Group was developed to improve the coordination of services for DHH children. Participation from individuals vary, and the UNHSP will evaluate the membership list to determine if groups are missing and recruit additional members accordingly.

4. Plan for using Use 25 percent of funding for family engagement and family support activities. A contract will be put in place with a statewide family-based organization, the Federation for Children with Special Needs, to fund a part-time parent position (Special Projects Coordinator).

This position provides outreach to families and providers. Jennifer Fleming was hired under the previous funding opportunity by the family-based organization. Funding will continue for this position. Funding will also be provided to the Federation to provide family support activities, education and training to families and stipends for family leaders who have a DHH child to participate on the Advisory Committee and in other UNHSP activities. Funding will also be included in this contract to cover the travel costs of a parent leader to the EHDI meeting, as state agencies are not permitted to pay for travel for non-state employees.

A contract will be put in place with Margaret Lee to implement direct DHH adult consumer-to-family support services to parents and families with a child newly identified as deaf or hard of hearing. No singular program exists in Massachusetts, and Ms. Lee will conduct an environmental scan to determine what DHH mentorship is available in Massachusetts, as well as what other states are doing. A cost analysis will be performed and assistance will be provided to the UNHSP to identify additional funds to carry out the recommendation.

Families report to the UNHSP that although information was provided to them through the Parent Information Kit and perhaps by their audiologist and early interventionist, they found that information sharing was most effective when done by another parent. UNHSP regularly facilitates opportunities for families to learn from each other. The program will host at least 5 events per year, both educational and social, in geographically diverse regions of the state. These events are planned by consumers and parents, and the social events are typically held at play spaces, children’s museums, sporting events and other similar locations that parents of young children typically visit. Educational opportunities will also be presented. Topics are set by parents. Funding will also be used to support parents to attend local conferences. Our presence, support, and facilitation of family-to-family connections will continue to be demonstrated at the annual family conference of the Federation for Children with Special Needs.

In addition to efforts provided by the UNHSP, the Federation for Children with Special Needs runs a program called Family TIES (Together In Enhancing Support). Families are trained to become support parents and are matched with another family to provide support over the phone. Training for parents of DHH children was provided in the last grant year, and UNHSP will publicize all scheduled trainings and encourage families to participate.

5. Plan to Consult with the HRSA-20-051 recipient (the Family Leadership in Language and Learning (FL3 Center) for resources, technical assistance, training, education, QI and evaluation to strengthen the infrastructure and capacity for family engagement and family support in the state/territory.

Consultation will be sought from the Family Leadership in Language and Learning Center (FL3) to strengthen the infrastructure and capacity for family engagement and family support. The FL3 website, webinars and workshops, eNews, and FL3 office hours resources will be utilized.

D. Facilitate Improved Coordination of Care and Services for Families and Children who are DHH

1. Plan to assess the status of coordination across early childhood programs and develop a plan to improve coordination and care services through a variety of mechanisms. The UNHSP participates in a Perinatal Team within the Department of Public Health. The Division of Pregnancy, Infancy and Early Childhood is also housed within the Bureau of Family Health and Nutrition. Recognizing that coordination across early childhood programs needed improvement, a tool called Facilitating Actionable Collaborations Tool (FACT) was developed. This tool is completed by each program and gives a snapshot of what the program's goals and objectives are and highlights areas of opportunities for collaboration. Early childhood programs within the Department that UNHSP collaborates with include: Welcome Family (home visiting program), Women Infants and Children (WIC), Massachusetts Early Childhood Comprehensive Systems (MECCS) and the Preschool Development Grant which has a strong focus on family engagement. This document will be continuously updated and will provide valuable information for enhancing connections with the Department.

The UNHSP collaborates with the MCDHH Children's Specialists, the Department of Early Education and Care (EEC) and the Department of Elementary and Secondary Education (DESE) on issues related to transition to school services, but there are opportunities for other collaborations. The UNHSP will approach EEC and DESE to discuss potential collaborations to improve services to families and children who are DHH.

Improvement of coordination and care will be examined and by the end of year 1, a written plan will be developed to measure the current level of stakeholder engagement. By the end of year 3, the UNHSP will demonstrate evidence of formal communication, training, and referrals.

E. Recipients will also be Expected to Participate in the Annual Early Hearing Detection and Intervention (EHDI) Meeting

1. Plan for budgeting for one or two staff and one family leader to attend the annual meeting. The UNHSP will send 1 UNHSP staff person and 1 EI staff person to the EHDI meeting. Additionally, a family leader will be funded to attend through a contract with the Federation for Children with Special Needs as state agencies are not permitted to fund travel for non-state employees. The UNHSP has formally shared program success through multiple presentations at this national meeting during the previous funding opportunity. These contributions are expected to continue.

2. Work with the HRSA-20-048 program recipient (the EHDI National Technical Resource Center (NTRC)) to implement the various initiatives that are listed in this NOFO and outlined in the work plan. The EHDI NTRC will be responsible for continuing to provide technical assistance when a need is determined by the recipient or the MCHB project officer.

Resolution of Challenges

The MA UNHSP is well positioned to meet the goals, objectives and requirements of this funding opportunity. Laws, regulations and guidelines are in place; the UNHSP has a dedicated staff with a lengthy history of working in the field of EHDI and includes bilingual staff, two parents, a consumer, and a dedicated epidemiologist to collect and analyze EHDI data and identify gaps and inequities in care. The UNHS Advisory Committee is actively engaged and has met for almost 20 years. The Stakeholder Group assists in the promotion of information sharing. The UNHSP has a comprehensive and well documented EHDI-IS that is integrated with other systems, developed to be sustainable, and easy to train new staff on. Families and consumers are involved in all aspects of the initiative, including having on staff two part-time parents of DHH children who were identified through newborn hearing screening and a full-time consumer. The parents lead efforts to provide parent-to parent-support and outreach to EI and providers. Family support events are held in order to facilitate families' meeting and gaining support from other families. An annual parent forum is held each year with a theme focused on DHH children. The UNHSP maintains a comprehensive webpage and a Facebook page. A Memorandum of Understanding is in place with the MCDHH to work collaboratively, including with the Children's Specialists. The UNHSP has expanded its partnership with Dr. Jane Stewart, the long-time MA Chapter of the American Academy of Pediatrics EHDI Champion and Advisory Committee appointed member. Letters providing information on the importance of early hearing loss identification and intervention are sent from Dr. Stewart to pediatricians.

Despite the UNHSP's strong potential to carry out the grant activities, challenges will exist in the creation and ongoing financial support of a DHH Mentorship program. Funding from this grant will help lay the foundation for such a program, but additional funding will have to be identified from other sources, including state/federal agencies, and private foundations to create the program envisioned. There is support for the concept within the state, but funding has not been secured.

Another challenge will be to continue to impress upon hospitals and Diagnostic Centers the importance of timely reporting in order to achieve the 1-3-6 goals. Ongoing training is needed due to staff turnover at birth hospitals and Diagnostic Centers. Data errors in the birth certificate are identified and addressed with Program Directors, but implementing system changes is not always in their control. Diagnostic Center audiologists provide individual level forms to the UNHSP with consent from the families. Audiologists do not always remember to ask for consent, and occasionally parents do not consent to have identifiable data sent to the UNHSP. Forms are not always submitted for every appointment until a confirmed diagnosis is made, or when an appointment is missed, losing valuable follow-up time with the family. Continued education and training will be provided, and data reports will be sent to facilities with performance measures.

Providing "on-demand" training and information to primary care providers is challenging. Educating primary care providers around 1-3-6 and the importance of timely follow up will be addressed using a co-trainer model of a parent and physician. Breaking down the EHDI system into pieces with actions associated with screening, diagnostic evaluation and early intervention will provide a blueprint for the provider to follow.

Evaluation and Technical Support Capacity

Quality improvement is embedded into all department programs and there has been a particular emphasis on it within the Division of Children and Youth with Special Health Needs. Antonia Blinn, BS, CHES, CSM, serves as the Director of Performance Management and Quality Improvement for the Department of Public Health. She leads QI efforts within the Department and has developed trainings to assist staff become more proficient in quality improvement methods. Several Division staff participated in Lean Six Sigma Green Belt training and performed an assessment on work flows.

Amarilys Triana-Walsh, the Lost to Follow Up Specialist, works closely with the Program Epidemiologist to identify areas of improvement in data reporting. Screening data are downloaded weekly, and fluctuations in referrals are an indication of data concerns at larger birth facilities. Ms. Triana-Walsh identifies concerns with data quality and completeness. Together with the Program Epidemiologist, targeted areas of concern are addressed and technical assistance is provided.

Project Director Sarah Stone has experience in Plan, Do, Study, Act cycles and other quality improvement methods. Ms. Stone has participated in Lean Six Sigma White Belt training and other Department-provided quality improvement trainings. She works closely with the Program Epidemiologist on program evaluation activities.

This project will receive in-kind support from the CDC funded Program Epidemiologist and other information technology staff. Martha Savaria Morris, Ph.D. is the Program Epidemiologist and reports to Hafsatou Diop, M.D., MPH, who is the Director of the Office of Data Translation and State Maternal and Child Health Epidemiologist. Dr. Diop has worked closely with the UNHSP for many years and provides advice on epidemiological studies. Dr. Morris has expertise in survey design and in SAS. Data is examined to identify disparities and to identify service areas of need, in addition to providing input into program policies. Dr. Morris provides data reports to hospitals and audiological diagnostic centers as well, as many other data reports on demand to assess performance. Lapses in protocol are identified and actions taken to prevent future data reporting concerns.

The Massachusetts EHDI-IS was created in house and is maintained by Department of Public Health Information Technology staff at no cost to the program. The database is in MS Access and is populated through a data download from the Registry of Vital Records. Information in the database includes demographics, primary care provider information, screening results and medical information. Letters to families can be automatically generated in the system. System updates are completed by the Systems Analyst who created it.

Organizational Information

The mission of the Massachusetts Department of Public Health is to prevent illness, injury, and premature death, to assure access to high quality public health and health care services, and to promote wellness and health equity for all people in the Commonwealth.

DPH envisions a Commonwealth in which all people enjoy optimal health. Massachusetts ranks among the healthiest of states according to comparative analyzes, but we face numerous challenges, including chronic and infectious disease, substance abuse, violence, preventable hospitalizations, and health disparities.

DPH provides programs to address specific diseases and conditions and offers services to address the needs of vulnerable populations. We also develop, implement, promote, and enforce policies to assure that the conditions under which people live are most conducive to health and enable people to make healthy choices for themselves and their families.

The Department is the recipient of over 100 federal grants, and has a dedicated budget specialist within the Bureau to provide support to staff implementing grants. This specialist works with Department level budget staff to ensure that all federal reporting requirements are met, and all costs are documented.

The Bureau of Family Health and Nutrition oversees the project through the Children and Youth with Special Health Needs (CYSHN) Division, which ensures that all MA infants, children and youth with special health needs and their families have access to comprehensive, family-centered, community-based, culturally competent and coordinated systems of care and support to live healthy lives. The Bureau also houses EI, Family Initiatives, WIC, Birth Defects, Care Coordination and many other programs that serve families with children with special health needs.

The UNHSP is highly invested in the CYSHN MCH Block Grant Priorities:

1. Percentage of children with and without special health needs having a medical home
2. Percentage of children with and without special health needs who received services necessary to make transitions to adult health care.

The CYSHN medical home priority provides the UNHSP with a sound foundation for work with providers. The transition priority recognizes that early experience and timely intervention leads to better outcomes in the future. According to feedback from many families, early identification of hearing loss will have a positive impact on DHH children in transitioning to adulthood and achieving independence.

Our Parent Forums have had teen leaders present on panels on a variety of topics to parents with young children. These presentations have received high praise, because families are helped by seeing their children's potential for the future. Health transition information can be imparted to the professionals serving the EHDI community, and a prime example is empowering children to care for their hearing aids, cochlear implants and other technology. Elaine Gabovitch, the Director of the Division for Children and Youth with Special Health Needs has presented to the diagnostic audiologists about this important topic, and the UNHSP will continue to stress the important role that these medical professionals have, considering the need for DHH adults to transition to adult hearing healthcare providers.

The Massachusetts Newborn Hearing Screening law continues to be one of the most comprehensive newborn hearing screening laws in the country. State hospital licensure regulations for hearing screening and guidelines were established for birth hospitals and audiological Diagnostic Centers. Program Director Sarah Stone, a consumer with hearing loss, has been with the program for 19 years. Lost to Follow Up Specialist Amarilys Triana-Walsh has been with the UNHSP for 14 years. She is bilingual/bicultural and has a tremendous wealth of experience in her role, which is crucial for the success of the program. Jennifer Fleming is contracted through the Federation for Children with Special Needs and serves as the part-time Special Projects Coordinator. Jennifer is a parent of a deaf son and spearheads the outreach to physicians and midwives. A small amount of state funding provided to the program supports an Outreach Specialist. The outreach included following up on missed screens and encouraging families to enroll their DHH children in EI. MCH Block Grant funding supports Richard Wentworth, the part-time Family Outreach Specialist who has a deaf son. This position provides parent-to-parent support and facilitates EI enrollment. CDC funding supports a full-time program epidemiologist and partially funds a Systems Analyst in its current cooperative agreement. A strong relationship with Vital Records and the Bureau's expertise with data systems made it possible to develop in-house a comprehensive and sustainable information system

The UNHSP has a contract with the Federation for Children with Special Needs as the family-based organization. This contract will continue in the new funding period. The Federation for

Children with Special Needs provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. The UNHSP works closely with the previously mentioned Family TIES to provide leadership training to families. Suzanne Gottlieb, the DPH Director of Family Initiatives also works closely with UNHSP staff.

Elaine Gabovitch, MPA, is the Director of the Division for Children and Youth with Special Health Needs. She formerly served as the Director of Family & Community Partnerships at the E.K. Shriver Center, and is an instructor in the Department of Family Medicine & Community Health of UMass Medical School, and Family Faculty for the LEND Program at the Shriver Center. She is also the parent of a young man with Autism Spectrum Disorder. Craig Andrade, LATC, RN, DrPH, is the Director of the Bureau of Family Health and Nutrition. Dr. Andrade is also a founding member of the Racial Equity Leadership Team (RELT) at the Department.

The UNHSP works closely with the Division of Early Intervention, and a data agreement is in place. The Director of Specialty Services participates in many UNHSP meetings and activities. In MA, all babies with any degree of permanent hearing loss is eligible for EI at no cost to the family. EI also funds the Family Sign Language Program, which is contracted through the Gallaudet Regional Center and is available free of charge to any family with a DHH child enrolled in EI. Connections are also strong with Newborn Screening, Home Visiting, Early Head Start and WIC. The UNHSP has a strong history of ensuring that all babies receive a hearing screen, a diagnostic evaluation and are enrolled into EI when indicated. Parents are provided information and support, and systems of care are developed to ensure that children who are deaf and hard of hearing receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social and emotional development.