

## Project Narrative

### 1. Introduction

The Massachusetts Department of Public Health (DPH), Universal Newborn Hearing Screening Program's (UNHSP) overall goal or aim for this project is to improve the health and quality of life of children with hearing loss and their families. Massachusetts (MA) fully recognizes that late identification of hearing loss and lack of access to appropriate and timely intervention services can have life-long negative consequences for infants who are deaf or hard of hearing and their families. In response to this serious public health problem, the MA Legislature passed and the Governor signed, one of the most comprehensive Universal Newborn Hearing Screening laws in the nation, (8.1 Chapter 243 of the Acts of 1998, An Act Providing for Hearing Screening of Newborns). The newborn hearing screening statute requires the following: 1) establishment of a broadly representative Advisory Committee, 2) universal hearing screening of all newborns, 3) audiological leadership at each birth facility to perform training of screening personnel, 4) DPH approval of audiological diagnostic centers that evaluate infants who fail the screen, 5) health insurance mandates to cover the cost of screening and follow-up audiological testing, and 6) amending the hospital licensure regulations to include a comprehensive section on hearing screening.

The UNHSP, Reducing Loss to Follow-up (LTF) after Failure to Pass Newborn Hearing Screening Project will focus on reducing loss to follow-up of infants who have not passed a physiological newborn hearing screening examination prior to discharge and address strategies to further reduce loss to documentation (LTD), which can contribute to infants and their families not receiving timely audiological testing and intervention services. Current successful strategies to ensure appropriate follow-up will continue to be deployed and will be reflected in the workplan. We will enhance our project by developing quality improvement exercises and implementing them throughout the project period. The Program Director and other staff have worked to develop a preliminary plan for a Quality Improvement Team and stakeholders have agreed to participate (Attachment 4.1 Letters of Agreement, Attachment 4.2 QI Team List).

This project will use quality improvement methodology (1. plan, 2. do, 3. study, 4. act PDSA). The quality improvement team will participate in a regular schedule of meetings (conference calls every two weeks and monthly meetings) and develop PDSA cycles targeted at loss to follow-up and loss to documentation. PDSA cycles will be rapid, studied and built upon when a successful strategy is identified. Massachusetts has invited the New England states and New York to participate in quarterly conference calls to share quality improvement methodologies and projects being carried out in the region. The state stakeholders have all readily accepted. MA took the lead in developing a Border Babies data sharing agreement and currently Vermont, Maine, Connecticut, Rhode Island, New Hampshire and Massachusetts have legal access to share border babies data on an on-going basis. A priority of these calls will be to develop quality improvement ideas to further improve early access to border data that will improve access to follow-up services.

The broadly representative Universal Newborn Hearing Screening Program (UNHSP) Advisory Committee has been meeting actively since 1999 and provides advice on quality improvement

activities. The program is data driven and disparities in care are identified and addressed. Extensive data analysis is provided on newborn hearing screening and follow-up annually and as needed to stakeholders. A quality improvement timeline was developed to ensure data is complete and allows for timely follow-up (Attachment 6.1 Quality Improvement Timeline). The MA birth hospital licensure regulations were amended to include a section on newborn hearing screening requirements. Written Newborn Hearing Screening Hospital Guidelines are established and were disseminated to providers to develop and submit protocols for approval to DPH. Numerous documents to ensure appropriate and culturally sensitive communication with families were distributed to stakeholders as well as written information for families on resources available in the state (e.g., brochures, Frequently Asked Questions, Parent Information Kit, next steps documents).

Staff work closely with birth facilities and download hearing screening results from the Vital Information Partnership Electronic Birth Certificate System (VIP) that is integrated with the Childhood Hearing Data System (CHDS). The CHDS is a sustainable fully automated system developed internally at DPH in 2001 and can be updated by internal programming staff as needed to improve the system and without cost to the program. Data is downloaded several times each week from VIP and staff make outreach calls to the more than 1,350 families whose infants do not pass the hearing screen to ensure follow-up appointments were made prior to discharge. Outreach information is documented in the CHDS. Outreach letters are developed and automatically generated by the CHDS and viewed as a critical resource to ensure follow-up.

DPH Approved Audiological Diagnostic Center (ADC) Guidelines are in place and are used to approve facilities. The Communications Coordinator and Program Director review and approve ADCs and there are currently 30 centers geographically dispersed across MA. The ADCs provide results, medical information and demographics via Secure Email and fax to the CHDS. The CHDS has provided comprehensive data that indicated that **1,939** infants were diagnosed with permanent hearing loss between calendar year 2002 and 2011 in MA.

#### Past Learning Collaborative Experience

The MA team had an aim to identify 100% of infants with hearing loss and focused on infants that missed the hearing screen (particularly those infants that are transferred at birth and may be at greater risk of having hearing loss). Data was analyzed to determine what factors made an infant higher risk of not receiving a hearing screening (e.g., transferred/Neonatal Intensive Care Unit infants and homebirths).

#### Aim Statement

Identify 100% of infants with hearing loss

- Focus on children who missed hearing screen
- Infants transferred from birth hospital to another facility
  - Infants in the NICU are at greater risk of having hearing loss
- Homebirths
  - Families are not connected directly to a screening facility at birth

The Quality Improvement Team's quality improvement methodology included: developing a **Plan**, which included questions to answer and ideas to test for change, **Do** (carrying out plan,

document problems, and make unexpected observations), **Study** (continuing to analyze and complete analysis of data), and **Act** (review what changes should be made and plan for next PDSA cycle).

The MA team chose the aim above to address the objective to screen all infants for hearing loss and data had indicated for several years that infants who were transferred to another facility at birth were often lost to screening or documentation of the screening. The team used calendar year 2006 data (most recent for multiple data sets) and determined that 27.9% of infants with permanent hearing loss had been transferred to a NICU and these babies were at higher risk of missing a screen. The overall hearing screening rate was 99.2%, but the screening rate for transferred/NICU babies was only 96.4% and almost 70% of transferred/NICU babies had one or more risk factor(s) for hearing loss. A survey was implemented to determine current screening methodologies at birth facilities across the state and the QI Team developed an Aim statement and carried out PDSA cycles to determine if infants in the NICU were medically eligible for hearing screening prior to transfer out to special care/nursery.

Our team studied age at transfer out, medical conditions, feasibility of screening more infants prior to transfer, and how many infants were medically ineligible for screening due to age or medical condition. The two hospitals that participated reviewed discharge summaries and consulted NICU medical personnel for additional information. They determined who was eligible for testing and drew conclusions regarding feasibility of screening prior to transfer. Findings were communicated to stakeholders and presented at the national Early Hearing Detection and Intervention (EHDI) Conference and included: 1) infants are nearly always transferred out when they are too young for screening, and 2) infants who meet the required age typically have medical conditions that preclude screening.

Barriers and breakthroughs included: 1) special care nursery nurses are generally the gatekeepers for newborn hearing screening decisions and 2) limited information is available to the UNHSP program when an infant is transferred due to the electronic access to the birth certificate not available at the receiving facility (UNHSP staff often track these infants through multiple facilities). Lessons learned included: 1) it is not realistic to consider requiring hearing screening prior to transfer, 2) if hearing screening data is not available to the receiving hospital, it should be assumed that no screen was performed, 3) birth facilities need guidance to ensure infants that spend time in a NICU receive screening via ABR, 4) it is difficult to monitor the number of screens when an infant is in more than one facility, and 5) it will require more staff time to ensure follow-up for NICU/transferred infants. Sustained improvement in number of unknown/missed screens was reduced by 50% (648 unknown missed infants in 2007 and 323 in 2011). The largest portion of unknown/missed infants in 2011 (187 infants) were homebirths. Information from this work informed policy when the new birth facility newborn hearing screening guidelines were established.

Please see Methodology Section for additional information.

## **2. Needs Assessment**

### Primary Target Population

Newborn hearing screening in Massachusetts is a population based program that serves all families with infants born in or residing in Massachusetts. Identifying hearing loss early obviates the negative developmental consequences to language and development that are associated with later diagnosis of hearing loss. Staff will oversee screening, audiological diagnosis, and access to intervention for this population statewide and consistent with the Early Hearing Detection and Intervention national goals and objectives and Healthy People 2010. Hearing loss data is integrated with the birth certificate, which provides demographic tracking and medical information. Diagnostic information is tracked through the Childhood Hearing Data System, which is populated by birth certificate, audiological and Early Intervention data. An agreement is in place with the statewide Early Intervention (EI) program to collect and analyze data to ensure follow-up of infants who are diagnosed as deaf or hard of hearing. Parents, caregivers and other family members are our primary contacts and demographic tracking information is available through the CHDS. The Deaf community, MA Commission for the Deaf and Hard of Hearing, hospital screeners, audiologists, physicians, EI providers, nurses, other birth facility personnel and related technology providers are all part of our target population.

#### Screening Population Served

According to the Massachusetts (MA) 2011 annual hearing screening data (most recent available), there were 73,513 occurrent births in MA and 99.5% of these infants had a documented hearing screening. There were 244 infants who were deceased, 32 declined screening, 136 were lost to documentation or missed, and 187 were homebirths. Approximately 73,500 infants will be followed each year of the project to ensure hearing screening occurs at birth and no later than one month of age and infants do not become lost to follow-up or lost to documentation. Of the infants that passed their screening, 71,550 (98.8%) passed before one month of age. Of the 1,364 (1.9%) infants who failed the screen, 94.1% failed by one month of age. There were 396 (29%) infants who failed the screen bilaterally and 968 (71%) failed the screen unilaterally. Birth facilities were required to make appointments at a DPH approved Audiological Diagnostic Center (ADC) and there are currently 30 approved centers across the Commonwealth. Approved centers submit audiological testing results to the UNHSP with informed consent through a secure electronic system that is downloaded into the Childhood Hearing Data System (CHDS). There were 179 infants diagnosed with hearing loss in 2011 and there were an additional 17 infants whose birth certificate indicated they passed the screen, but were documented with hearing loss (>50% of these infants were diagnosed within three months and many had a known risk indicator for hearing loss) for a total of 196 infants with hearing loss in 2011.

#### Did Not Pass Hearing Screening Population

There were 1,364 infants who did not pass the hearing screening. Of these infants, 1,004 (74%) were documented to have normal hearing. Of those diagnosed with normal hearing, 887 infants were diagnosed by three months, 65 were diagnosed by six months, 49 were diagnosed after six months and 3 were age unknown. Of the infants diagnosed with hearing loss, there were 179 (13.1% or 1:8) infants with permanent hearing loss. Of the infants diagnosed with permanent hearing loss: 123 were diagnosed before three months of age, 30 infants were diagnosed after three months and before six months, 24 infants were diagnosed after six months and two were diagnosed at an unknown age. There were also 124 (9.1%) of infants with non-permanent, transient hearing loss.

### Infants with Hearing Loss in EI

All infants with permanent hearing loss are eligible for early intervention services. Of the infants diagnosed with hearing loss, 155 (86.6%) were confirmed to be referred to EI and 138 (77.1%) were enrolled in EI (93 before six months, 31 after six months and before 12 months, nine enrolled after 12 months and five infants were enrolled and the age of enrollment was unavailable). There were seven infants receiving only monitoring services and 34 infants (19.0%) who had no documented EI services (one infant was deceased, 13 declined services, 9 moved out of jurisdiction.)

### Hearing Loss by NHS laterality

According to 2011 data, infants who fail the hearing screen bilaterally are more likely to have hearing loss (1:4 infants who fail the screening bilaterally were diagnosed with hearing loss). Infants who fail the screen unilaterally have a 1:11 chance of having hearing loss. It is important to note that 29 (1:3) of the children who failed the screen unilaterally and were diagnosed with hearing loss were actually diagnosed with bilateral hearing loss.

### Infants without a Diagnosis/Undetermined Diagnosis

There were 181 (13.3%) infants who did not pass the screen and did not have a confirmatory diagnosis of normal hearing or hearing loss. Of these infants, 92 (6.7%) had an audiological diagnostic appointment that did not produce a conclusive diagnosis, four infants were deceased, 35 families declined consent, nine moved out of jurisdiction and 41(3.0%) were LTF or Lost to Documentation (LTD).

### Barriers in Service Areas

There were 181 infants who had no diagnosis confirmed in 2011. Of these infants, there were 92 infants who had an appointment and no confirmatory diagnosis, 35 parents declined to provide information on their infant's audiological testing, 4 infants were deceased, 9 moved out of state, and 41 were lost to follow-up. Through this funding we will carryout quality improvement methodologies to understand what happened to infants in the "in progress" category and decrease the number of infants that become lost to follow-up. We have been tracking the "in progress" category since 2007 and it has only decreased a small percentage from 13.9% to 13.3% in 2011. Data indicates that the number of audiological diagnostic forms has decreased requiring more staff time to track diagnostic results and other medical and demographic data.

### General Highlights of Maternal Demographics in Massachusetts

According to "Massachusetts Births 2010, MDPH, Bureau of Health Information, Statistics, Research and Evaluation" published in March 2013, the teen birth rate has declined (17.1 births per 1,000 woman ages 15-19), although the birth rate for Hispanic teens was 4.7 times that of White women (49.3 vs 10.4 births per 1,000 women ages 15-19). The Black infant mortality rate was 2.5 times higher than the White infant mortality rate. Mothers who had adequate prenatal care increased to 84.9% and 35.8% of these mothers had their prenatal care covered through public programs. Over 23% of infants were delivered through cesarean delivery. The number of women who planned to breastfeed at time of discharge was at a record high of 83%. The percentage of low birth weight infants was 7.8% and the percentage of preterm infants delivered before the 37<sup>th</sup> week of gestation was 8.6%. Health and other disparities were evident in mothers

who had a high school education or less as they were less likely to receive adequate prenatal care, more likely to report smoking during pregnancy, more likely to have publicly financed prenatal care, and more likely to deliver low birth weight infants (less than 2,500 grams). The percentage of births to non-US-born mothers was 27.4%. UNHSP staff have access to the preferred language of the mother in the birth certificate and this is reviewed prior to initiating outreach calls (one UNHSP staff member is bilingual/Spanish speaking and uses a telephone interpreting service for other languages). Recent analysis of UNHSP data indicated that close to 6% of mothers preferred to receive information in Spanish.

### **3. Methodology**

#### Overall Goal/Aim

The overall goal of this project is to improve the health and quality of life of children with hearing loss and their families in Massachusetts by reducing the number of infants who are lost to follow-up from four main service areas: 1) physiologic newborn hearing screen at birth, 2) audiologic diagnostic evaluation upon a hearing screen referral, 3) enrollment in the Early Intervention program upon a hearing loss diagnosis, and 4) identification of children with hearing loss that occurs after the newborn period as early as possible. Massachusetts has demonstrated a commitment to newborn hearing screening and follow-up and has achieved almost 100% of infants screened for hearing loss annually for more than several years and a comprehensive follow-up system that ensures infants and their families do not become lost to follow-up or lost to documentation. Proven strategies carried out from previous project periods will be continued and include the following:

#### Primary Objectives

The primary objectives that will be carried out and measured include the following:

- 1) Ensure screening of all newborns at birth or prior to one month of age,
- 2) Rule out or confirm hearing loss in infants who do not pass their newborn hearing screening by three months of age,
- 3) If a hearing loss is confirmed, the family and the infant will be entered into a program for early intervention as soon as possible and before the infant reaches six months of age,
- 4) Track infants and young children diagnosed with hearing loss through the sixth birthday and provide resources and supports to families.

Process Objectives and Activities include:

- Collecting and approving hospital screening protocols
- Collecting individual data on screening results through the birth certificate, including demographics and medical risk indicator information for the mother and child
- Providing families with information about newborn hearing screening prior to the screening and written documentation of the results of screening,
- Providing information in a culturally sensitive manner in the preferred language of the parent
- Providing information necessary for primary care clinicians to provide care, including faxing letters regarding families we cannot reach or families that missed appointments,
- Ensuring that birth facilities make audiological diagnostic appointments prior to discharge for families whose newborn failed a hearing screening.

Staff will be responsible for the following:

- 1) Identify infants/families who require follow-up testing,
- 2) Perform outreach to the family prior to the follow-up appointment to be sure the family has the information and supports necessary to get to the appointment,
- 3) Document all outreach activities in the CHDS,
- 4) Follow-up with birth facilities and families on any child who missed a screening,
- 5) Obtain results of appointments through informed consent from ADCs for infants and children through the sixth birthday,
- 6) Enter diagnostic data (including high risk information) into the CHDS,
- 7) Provide family support to parents at diagnosis (DPH approved audiologists are provided with UNHSP Parent Information Kits that are available in Spanish and English and are required through UNHSP guidelines to be given at diagnosis) and parent to parent support is provided,
- 8) Collaborate with other early childhood programs to ensure young children with hearing loss identified after the newborn period are connected to services,
- 9) Provide parent to parent support and statewide resources to families whose children are identified with hearing loss after the newborn period,
- 10) Providing training to staff that includes training on public benefits available to families served by the program, developing quality improvement skills and understanding the Affordable Care Act and other changes to health benefits that may affect families.

Data that will be collected and used to document progress on the objectives include but are not limited to the following:

- Number of infants screened for hearing loss by one month of age
- Number of infants screened for hearing loss by more than one month of age
- Number of infants who missed a hearing screening
- Number of infants who passed a newborn hearing screening
- Number of infants whose parent refused screening for sincerely held religious beliefs
- Number of home birth infants, including number screened for hearing loss
- Number of infants who did not pass a newborn hearing screening
- Number of infants who did not pass a newborn hearing screening and who received follow-up audiological testing before three months of age
- Number of infants who did not pass a newborn hearing screening and who received follow-up audiological testing after three months of age
- Number of infants who did not pass a newborn hearing screening and who did not receive audiological follow-up after six months
- Number of infants who were diagnosed with normal hearing after not passing a newborn hearing screening and receiving follow-up audiological testing
- Number of infants diagnosed with hearing loss through UNHSP who were receiving EI services and documented in the EI Information System by six months of age
- Number of infants diagnosed with hearing loss who passed the newborn hearing screening and were entered into the EI Information System with a diagnosis of hearing loss
- Number of infants who did not pass a hearing screening who received an audiological diagnostic appointment and degree or type of hearing loss was undetermined (diagnosis pending)

- Percent of forms received from ADCs without consent (aggregate data is submitted on these children)
- Average/median age of diagnosis of hearing loss by months
- Number of children who are not enrolled in EI by six months of age
- Number of outreach calls to parents
- Number of families who received parent to parent support at diagnosis
- Number of UNHSP brochures distributed in 13 languages
- Number of Parent Information Kits distributed in English
- Number of Parent Information Kits distributed in Spanish
- Number of DPH Approved ADC Meetings and number of providers who received training
- Number of DPH UNHSP Advisory Committee Meetings
- Number of technical assistance encounters and number of trainings for Head Start Programs and Home Visiting Programs
- Number of families who participated in program/state sponsored activities
- Number of states that signed border babies agreement

Please see Attachment 6.2 flow diagram that illustrates program activities and Attachment 6.3 Logic Model. Quality Assurance reports are generated and birth facility report cards are developed and disseminated each year. Details of the quality improvement methods are below and the workplan will illustrate the activities that will be carried out for the Project.

This funding will allow MA to continue to employ successful strategies carried out for the past several years and included in the guidance for this project including:

- Scripting the screeners' messages to parents
- Using FAX-back forms between multiple providers
- Ascertaining the name of the infants primary care provider through the Vital Information Partnership (VIP) Electronic Birth Certificate system and subsequent follow-up calls with families
- Identifying a second point of contact for the family through the VIP and follow-up calls
- Overseeing hospitals making rescreening or audiology appointments prior to discharge
- Ensuring birth facilities make rescreening and audiological appointments for the infant prior to hospital discharge and follow up with the family to ensure the appointment was made soon after discharge and until diagnosis is achieved
- Making reminder calls to parents to be sure follow-up appointment occurs and ascertain whether or not family needs an interpreter if the families preferred language is other than English
- Providing parent to parent support at diagnosis of hearing loss to ensure prompt access to Early Intervention (EI) and unbiased information about MA services, and continuing follow-up until enrollment in EI is achieved
- Improving data tracking systems, including reports to birth facilities and DPH Approved Audiological Diagnostic Centers (ADC), to ensure infants transferred at birth are not lost to follow-up

The Massachusetts UNHSP will continue to focus efforts on sustainability of the system for newborn hearing screening and intervention and focus on the following:

- Conduct on-going data analysis to determine barriers to follow-up and disparities to receiving care
- Continue quality improvement efforts related to lost to follow-up and lost to documentation and analyze data to assess progress
- Utilize small tests of change theory (plan, do, study, act) when testing new activities
- Collect hospital screening protocols for review and approval
- Screen all newborns at birth or prior to one month of age
- Collect screening results, demographic and medical data on all infants born in the Commonwealth each year
- Perform outreach to the approximately 1,300 families whose newborn does not pass a hearing screening to ensure follow-up
- Approve protocols for DPH Approved Audiological Diagnostic Centers and continue to encourage centers to enroll in the Early Hearing Detection and Intervention, Pediatric Audiology Links to Services (EHDI PALS)
- Provide information and services in a manner that respects the diversity and cultural richness of populations served and accommodates the preferred language of the family
- Document that hearing loss is ruled out or confirmed in infants who do not pass their newborn hearing screening by the time they are three months of age
- Work with the family to enroll the infants diagnosed with hearing loss into a program for early intervention as early as possible and before six months of age
- Provide unbiased parent to parent support, including a comprehensive Parent Information Kit (PIK), to families when children are diagnosed with hearing loss
- Develop resources for families that foster early literacy for deaf and hard of hearing infants
- Partner with families at all decision making levels of program planning
- Ensure that infants and young children with hearing loss receive ongoing care within a medical home, including collaborating with state medical home activities
- Partner with Head Start and Home Visiting to ensure young children with hearing loss receive appropriate screening in early childhood settings
- Work with the MA, EI Partnering for the Success of Children with Hearing Loss initiative to ensure families have early access to appropriate services and that local EI Programs continue to have a designated hearing loss contact staff member who is adequately trained to support families and providers
- Identify training opportunities for EI contacts, including webinar training with DPH approved audiological centers and email blasts
- Conduct outreach efforts to assess the adequacy of public/private insurance to pay for services needed
- Work with the Title V Home Visiting initiative, statewide WIC Program, Head Start, DPH Immunization, School Health, Birth Defects Programs, and Prevent Blindness America to be certain that providers are educated about the importance of newborn hearing screening and follow-up
- Carryout evaluation and monitoring activities to ensure goals and objectives are met and families are satisfied with the services they receive

### MA Quality Improvement Experience

The Project Director for this grant, Janet Farrell, organized the first newborn hearing screening quality improvement team in MA and has strong working relationships with many stakeholders working in the field. She has been trained in quality improvement methodology and provided coordination and leadership to carryout PDSA cycles. She was actively involved in the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative on the national level as a subject matter expert on newborn hearing screening and follow-up. She has continued to participate on workgroups with NICHQ focused on LTF, data collection and intervention. The family representative Richard Wentworth, Sarah Stone Communications Coordinator and Margaret Toro, Au.D, CCC-A, Director of the Brigham and Women's Hospital Newborn Hearing Screening all participated in the first quality improvement collaborative project and have agreed to participate in the new team, which will include additional members.

### New Areas to Address through Quality Improvement

MA will ensure infants and their families do not become LTF/LTD by meeting the Healthy People 2010 Objectives for Newborn Hearing Screening and Follow-up: Increase the proportion of newborns who are screened for hearing loss by no later than one month of age, have an audiological evaluation by age three months, and are enrolled in appropriate intervention no later than six months of age (2012 data will be finalized soon and compared to determine if there are additional areas to address). Noted areas in the 2011 data that will be addressed through this project include the following:

Screening: 1) 32 families declined screening; 2) 136 were unknown/missed screening/lost to documentation; 3) 187 homebirth infants did not receive a hearing screening or were lost to documentation.

Later diagnosis/infants with normal hearing: 1) 65 infants were confirmed to have normal hearing after three months, but by six months; 2) 49 infants were confirmed to have normal hearing after six months; 3) three infants were confirmed to have normal hearing at an unknown age.

Later diagnosis/infants diagnosed hearing loss: 1) 30 infants were diagnosed after three months and before six months; 2) 24 infants were diagnosed after six months; 3) two infants were diagnosed at an unknown age.

Infants with undetermined diagnosis (were seen and diagnosis was not achieved): 92 infants (6.7%) had at least one audiological diagnostic appointment and do not have a conclusive diagnosis

Declined consent: 35 families at audiological testing

Lost to follow-up: 41(3.0%) were LTF/LTD (statistics indicate that our program may be missing children with HL in this category)

### Proposed Quality Improvement Cycles

Quality improvement theory will be used and goals and objectives will be Specific, Measurable, Attainable, Realistic and Timely (SMART). Process outcomes will be monitored and successful work will be built upon. Plan, Do, Study, Act (PDSA) cycles will be developed and implemented and successful changes will be spread across the system. Staff will measure data throughout the QI cycle and present the data to the QI Team and stakeholders through data and dashboard graphs and charts.

Overall Aim: Ensure 100% of infants receive hearing screening at birth or no later than one month of age, Confirm hearing screening results and follow-up on 100% of infants who do not pass or miss a hearing screen to be certain follow-up occurs, Ensure audiological follow-up no later than three months of age for all infants who do not pass the screen, and track enrollment into Early Intervention for all newborns to ensure access prior to six months of age.

The QI Team will identify a team leader and team facilitator who will go over the model for improvement to be used (PDSA). A regular schedule of meetings will be established and include a focus on balanced participation by all members. Ground rules for communication will be clear and assignments will be recorded with timelines. QI experience will be shared with the other New England states and New York during quarterly conference calls.

- 1) Analyze data and determine which facilities had families who refused screening, test providing technical assistance to hospital staff and contacting program director and audiologist at facility
- 2) Analyze data on 41 infants “lost to follow-up” infants to determine reasons why, look for disparities in care and geographic challenges
- 3) Lower number of infants in the “diagnosis pending” category by analyzing data to understand where these children received their first appointments and look at recommendations to determine where the infants should have gone for follow-up (e.g., ENT)
- 4) Identify infants in “diagnosis pending” category with additional risk indicators for hearing loss and identify two facilities to call five families to determine if they are receptive to return
- 5) Test how sending monthly reports to one audiological diagnostic facility to improve tracking missing audiological diagnostic data and repeat with other facilities if successful
- 6) Determine timing of filing of birth certificates for homebirths to determine if early outreach can improve number of homebirths screened
- 7) Determine timing of filing birth certificate for resident births born out of state and develop strategies to improve access to timely screening results
- 8) Approach two centers who registered for EHDI PALS (pediatric audiology links to services) who are not on the DPH approved audiological center list and determine willingness to provide data with informed consents
- 9) Improve timeliness of audiological diagnostic reporting and cleaning of missing information

#### Advisory Committee

The Massachusetts Universal Newborn Hearing Screening Program Advisory Committee is mandated by state law. This broadly representative group of dedicated family members, consumers, clinicians, researchers and other professionals has been meeting since January 1999. The Chair of the Committee is Barbara Herrmann, Ph.D., CCC-A from Massachusetts Eye and Ear Infirmary. The meetings are subject to the MA open meeting law and agendas are published on line prior to the meetings. UNHSP staff organize the meetings and distribute agendas, minutes and other materials. The Committee advises the UNHSP on policy, technology, intervention, communication with families and has greatly contributed to establishing the regulations, hospital and audiological guidelines.

### Title V, Early Head Start and Homevisiting

The UNHSP is a Title V Program in the Children and Youth with Special Health Care Needs Division. Staff collaborate with all early childhood programs and have assisted in providing technical assistance and training to Head Start and Home Visiting in areas related to early childhood screening. The Project Director has taken part in statewide trainings and identified audiologists to provide technical training on appropriate screening methodologies in early childhood. This has included working with the Early Childhood Hearing Outreach (ECHO) Project through the National Center for Hearing Assessment and Management.

### Sustainability Plan

Chapter 243 of the Acts of 1998 ensures that hearing screenings will occur in the Commonwealth for all newborns after the period of Federal funding ends. Amending the hospital licensure regulations to have an extensive section on requirements for newborn hearing screening makes it possible for the initiative to be carried out uniformly at the birth facility level statewide. Using the birth certificate to populate data and creating the CHDS in-house and without cost to the project assists with sustainability. A comprehensive manual has been developed that provides details on the program and can be used for new staff or as staff change duties. Cross-training is a priority for the program. The success of the initiative has much to do with dedicated staffing and due to economic challenges at the state level, there is not a plan in place to fund the current staff paid under the grant if Federal funding was no longer available.

### **4. Workplan**

Please see (Attachment 1 Workplan), which includes more specific information about QI projects.

### **5. Resolution of Challenges**

States across the nation are experiencing budgetary challenges and reduced federal funding has an impact on our Bureau, Division and Program. Reduced funding affects staffing the UNHSP and represents a challenge to the continued success of the program. Reduced funding will limit our ability to organize some of our family support activities and our Annual Parent Forum may have to be held every other year. Staff work hard to identify low cost options for bringing families together and supporting families to attend other events that would be too costly for the UNHSP to organize independently, but even these low cost activities could be at risk. Communicating with families through e-blasts and Facebook have been low cost options to keeping our program highly visible to families.

The UNHSP experienced some data challenges when the Vital Information Partnership (VIP) electronic birth certificate was implemented. Hearing screening results were not entered consistently. As a result, UNHSP staff developed reports for birth facilities to update birth information and ensure it was complete so follow-up could occur. Currently, one of the largest birth facilities has difficulty with entering data into the VIP and staff has requested lists of infants who fail the screen to ensure families receive appropriate and timely appointments. Tony Sousa was recently hired as the new Registrar of Vital Records and Statistics and problems with the birth certificate are being addressed.

## 6. Evaluation and Technical Support Capacity

Staff meet monthly to review EHDI data and monitor program activities. The Quality Improvement Team will meet regularly through conference calls every other week and monthly meetings will be held. Hafsatou Diop, MD, MPH is the Director of the Office of Data Translation and State Maternal and Child Health Epidemiologist. She will participate and provide technical support on our quality improvement team. Data will be collected in the Childhood Hearing Data System (CHDS) and annual data, as well as Quality Improvement data/trends, will be reviewed by the team regularly and presented to the Advisory Committee. CHDS data is analyzed using SAS and other high level data analysis software and has been actively used since 2001. Particular attention will be paid to health disparities as they relate to underserved groups and cultural and linguistic minority populations. Geographic disparities are identified and addressed. EHDI data will be submitted to CDC annually and include demographic data for the state. Stakeholders, particularly families with children with hearing loss, will be involved in the quality improvement efforts and there will be participation by other early childhood venues, such as EI, Head Start and Home Visiting (see Accomplishment Summary for information on past evaluation projects and activities).

Data are integrated with the state birth certificate data, which provides demographic and medical information on mothers and their infants. Newborn hearing screening data is also integrated into the Pregnancy to Early Life Longitudinal Database (PELL). This database is the core of our data system, providing the program with access to birth and fetal death files linked to the hospital discharge records of mother's delivery and child's birth. Program and state agency data from EI, Birth Defects, WIC, UNHSP, Substance Abuse Services and Assisted Reproductive Technology are among the selected data that are linked or in the process of being linked to the core Pregnancy to Early Life Longitudinal Database (PELL). Staff have performed analysis using this data on Down Syndrome and Orofacial clefts and hearing loss and just began preliminary analysis on utilization of cochlear implants in the state.

During Year 1 of the funding cycle, staff will work with the DPH Legal Office and statewide EI Program to determine access to EI outcome data. This will include a formal request from the legal office and obtaining approval from the EI Program. Data variables that are of mutual interest to UNHSP and EI will be decided upon and a protocol for evaluating the data will be written. Staff will investigate the feasibility of integrating this data with PELL data.

Staff have presented project findings at all of the national EHDI conferences, including quality improvement experiences. Project staff have two abstracts accepted for the 2014 EHDI Conference and the Project Director will be participating in a panel with the American Academy of Pediatrics on Lost to Follow-up. Project staff participated in a number of national evaluation projects and have published two articles in peer reviewed journals ("Evaluating Loss to Follow-up in Newborn Hearing Screening in Massachusetts, *Pediatrics*, February 2008, and "Evaluating Families' Satisfaction with Early Hearing Detection and Intervention Services in Massachusetts", American Speech-Language-Hearing Association (ASHA), *American Journal of Audiology*, June 2007). The Project Director also published "Developing a Strong Early Hearing Detection and Intervention Program" in the *ASHA Leader* in March 09.

## **7. Organizational Information**

### Organizational Mission and Structure

This Project is a program of the Massachusetts Department of Public Health, whose mission 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 of the Commonwealth. The Bureau of Family Health and Nutrition oversees the project through the Children with Youth with Special Health Care Needs Division (DCYSHCN), which ensures that all MA infants, children and youth with special health care needs and their families have access to comprehensive, family-centered, community-based, culturally competent and coordinated systems of care and supports to live healthy lives. The DCYSHCN is in the Bureau of Family Health and Nutrition (Attachment 5 Project Organizational Chart), which implements and evaluates public health programs in close partnership with families and consumers to ensure that they are relevant, effective, accessible and meet the ongoing needs of children and families. Staff have worked for many years with the American Academy of Pediatrics (AAP) representative for MA, Janet Stewart, M.D. who provides ongoing technical assistance and support to our program. The programs are guided by the following six core outcomes for CYSHCN:

- 1) Families with children and youth with special health care needs will partner in decision making at all levels and are satisfied with the services they receive;
- 2) Children and youth with special health care needs will receive regular ongoing care within a medical home;
- 3) Families with children and youth with special health care needs will have adequate private/public insurance to pay for the services they need;
- 4) Children will be screened early and continuously for special health care needs;
- 5) Community based service systems will be organized in ways that families can use them easily;
- 6) Youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work and independence (MA DCYSHCN has expanded the definition of transition to include transitions during early childhood and throughout the life course).

### Project Staff

The Project Director has been with the program since it began in 1998 and is supervised by Ronald Benham, Bureau Director and statewide Early Intervention (EI) Part C Coordinator. Mr. Benham is an expert on national policy and has participated in many workgroups focused on early hearing detection and intervention (EHDI). MA EI policy requires that all infants and children with permanent hearing loss are eligible for the program. Our state abolished parent fees for EI this past year, to improve early access to these important intervention services.

Funding from this grant will be used for our Communications Coordinator (CC), Sarah Stone who oversees protocol approval for birth facilities, diagnostic centers and communication to providers and families. The Family Outreach Specialist (FOS) Richard Wentworth has been hired in a state position and is the parent of a young child identified with hearing loss through the UNHSP. The FOS contacts all families with infants and young children diagnosed with hearing loss to be certain they received a Parent Information Kit (available in English and Spanish) and become enrolled in the statewide EI system. Kathy O'Connell, Outreach Specialist (OS) is a full-

time employee focused on ensuring homebirth families are aware of the importance of hearing screening and is also responsible for overseeing the complicated tracking of infants who are transferred at birth. Receiving hospitals do not have access to the birth certificate and screening results must be relayed to the program and tracked through often faxed transmittal forms. She also oversees distribution of program brochures that are available in 13 languages.

Dedicated staff, including the Program Director, Janet Farrell and Sarah Stone, Communications Coordinator has been with the UNHSP since the program was established by the Department of Public Health (DPH). Richard Wentworth, Family Outreach Specialist and Kathy O'Connell, Outreach Specialist dedicated themselves to working on issues related to LTF/LTD (Attachment 2.1 Staffing Plan, 2.2 Job Descriptions and Attachment 3 Biographical Sketches of Key Personnel). The UNHSP works closely with other BFHN programs, including: EI, Perinatal (including Maternal, Infant, and Early Childhood Home Visiting Program), and statewide Women, Infant, and Children (WIC) Programs. Ron Benham is the Director of the Bureau of Family Health and Nutrition and Janet Farrell, UNHSP Program Director is on the senior management team in the Children and Youth with Special Health Care Needs Program. Ms. Farrell serves on the New England Newborn Screening and Birth Defects Advisory Committees and New England Regional Genetics Group (NERGG Board of Directors and works closely with the New England Genetics Collaborative (NEGC). Staff collaborate on an on-going basis with DPH partners including the Perinatal and Home Visiting Programs, New England Newborn Screening Program, Birth Defects Program, Pregnancy to Early Life Longitudinal Study, Registry of Vital Records and Statistics, Immunization Program, MA Commission for the Deaf and Hard of Hearing, statewide Head Start Program, Office of Early Education and Care and Prevent Blindness America and others.

#### State Law, Regulations and Guidelines

MA has one of the most comprehensive newborn hearing screening laws in the country and >99.5% of infants are screened each year for hearing loss. The hospital licensure regulations were amended to include a section on newborn hearing screening requirements, including communicating with families about the screening and results and ensuring families receive information in their preferred language. MA Newborn Hearing Screening Hospital Guidelines are in place and were updated in collaboration with the DPH Medical Director, Lauren Smith, M.D. and the UNHSP Advisory Committee, and distributed to birth facilities in January 2013. Birth facilities amend protocols as needed and they are collected from the UNHSP every five years for review and approval. Staff are in the process of reviewing protocols based on the 2013 revised NHS Birth Facility Guidelines.

Healthy People 2010 also addresses access to the use of hearing aids and other technologies and MA Chapter 233, An Act Providing for Hearing Aids for Children was recently passed. This law requires health insurance companies to cover the cost of hearing aid(s) for children through age 21 years and up to [REDACTED] per aid every 36 months. Our staff has been working to educate families and providers on this new law and will continue to do so through the next project period.

Please see (Attachment 7 Accomplishment Summary and Attachment 8.2 Acronyms) for more information.