

Workplan

The workplan is a combination of routine activities carried out that have been a proven success to address lost to follow-up in Massachusetts and Quality Improvement exercises developed to address segments of the system (identified through data collection) that have indicated areas requiring improvement to reduce (Loss to Follow-up/Loss to Documentation) LTF/LTD.

Staff Involved with the Project

Communications Coordinator (CC) 1.0 FTE, Outreach Specialist (OS) (1.0 FTE), Family Outreach Specialist (FOS) (.58), staff paid off other funds: Program Director (PD) (in-kind), UNHSP Epidemiologist (EPI), Lost to Follow-up Specialist-focused on families whose preferred language is Spanish (LFS), Quality Improvement Team (QIT)

Quality Improvement Activities

Completion dates of the plan, do, study, act (PDSA) cycles take into account time necessary for obtaining complete data and reviewing data over a period of time. Additional process and outcome measures will be determined as PDSA cycles are carried out. Aim statements were chosen based on improving LTF/LTD and include the following:

Aim Statement 1:

The UNHSP will determine which birth facilities had families who refused hearing screening and reduce the number of refused hearing screening by 50% across the state by the last quarter of 2014 (continue PDSA cycles to address this concern)

- Three birth facilities will be provided technical assistance to reduce number of refused hearing screenings (provide information on state data and non-invasive nature of screening)
- Facilities in first PDSA cycle will reduce number of refused screens by 50% by second quarter of data analysis

Changes/activities	Start date	Estimated completion	Staff partner	Process	Outcome
Reduce refused screening by identifying facilities who have families who refuse	4/14	12/14	PD,CC, FOS, QIT, EPI,OS, LTFS	Analyze past quarterly data, identify facilities with refused screenings, provide technical support to birth facility staff, analyze next quarter data	Reduce number of infants who refused hearing screen

Plan: Analyze data and meet with QI team (present data on refused screens), Do: contact sample of three facilities with highest number of refused hearing screens and provide technical assistance, Study: review next quarter data to see if there was improvement, Act: According to results and spread positive change to other facilities (continue to monitor statewide data over time/create new PDSAs to further improve this problem)

Aim Statement 2:

Reduce LTF/LTD by 20% by last half of calendar year 2014, by analyzing data on 2011 and 2012 infants “lost to follow-up” to determine disparities that make infants at higher risk of LTF/LTD, identify number of infants who failed screen bilaterally (higher risk for hearing loss),

and identify those that are known in the system as being later identified. Develop algorithm to improve outreach to families whose infants are at higher risk of LTF/LTD.

- Identify common factors associated with lost to follow-up
- Provide technical assistance to 100% of birth facilities and DPH Approved Audiological Centers in areas with geographic, cultural or other disparities identified
- Prioritize outreach efforts to address cultural barriers

Changes/activities	Start date	Estimated completion	Staff partner	Process	Outcome
Reduce LTF/LTD Identify infants/families at higher risk	5/14	4/15	PD,CC, FOS, QIT, EPI,OS, LTFS	Analyze cultural/geographic, facility where infant was born, other; determine how many bilateral refers; analyze quarterly data	Reduce LTF/LTD by 20% and develop outreach algorithm to prioritize families at risk of LTF

Plan: Analyze 2011 and 2012 LTF/LTD data for disparities in care and review with QI Team, Do: Collect recommendations for outreach to at risk population and develop algorithm for Advisory Committee review and comments, Study: Use comments and other feedback, particularly from families whose infants was LTF/LTD, Act: Implement at risk for LTF/LTD algorithm with outreach staff and analyze data on a quarterly basis and report back to QI Team. Develop new resources for families as needed. Consider additional PDSA cycles.

Aim Statement 3:

By the third quarter of calendar year 2014 data, lower the number of infants in the diagnosis pending category by 20% and identify those with additional risk indicators for hearing loss.

- Identify two audiological centers with high number of diagnosis pending and follow five infants (per center) to determine where child was referred (e.g., Ear, Nose and Throat doctor) and what happened
- Determine median date children received first audiological appointment

Changes/activities	Start date	Estimated completion	Staff partner	Process	Outcome
Lower number of infants in diagnosis pending category by 20%	4/14	12/14	PD,CC, FOS, QIT, EPI,OS, LTFS,	Work with two centers to follow five infants each who were diagnosis pending to determine why final diagnosis was not achieved, contact families for additional information	Reduce number of infants who do not receive a definitive diagnosis after failing hearing screen

Plan: Analyze data and present to QI Team, identify two centers to track five children each in diagnosis pending category, Do: Follow what happened after first appointment, including where they were referred and contact families for additional information on follow-up, Study: Look for common themes in what happened, Act: Share lessons learned with DPH approved audiological centers and plan additional PDSAs as needed.

Aim Statement 4: Test sending monthly data quality reports to one audiological center to improve percentage of missing audiological diagnostic results and repeat with other facilities if found successful to improve LTF/LTD and earlier access to outreach

- Analyze missing data for one quarter and determine relationship to LTF/LTD
- For children diagnosed with hearing loss that were in the “missing data” category analyze data on 10 children to determine if they received diagnosis and access to intervention later

Changes/activities	Start date	Estimated completion	Staff partner	Process	Outcome
Send monthly data quality report instead of waiting to send reports when cleaning data	9/14	2/15	PD,CC, FOS, QIT, EPI,OS, LTFS	Analyze data to determine center with highest amount of missing data, engage leadership at the facility, provide monthly report to update data	Reduce missing data, allowing for timely outreach and follow-up

Plan: Analyze data to determine missing data as reported by families during initial outreach that determined family had an appointment and other mechanisms, Do: Develop report and send to identified person who will update it at the center, Study: review ten random records at the state level of children who had missing information to determine if they received timely follow-up and intervention, Act: Test with other centers or plan new PDSA cycles. (discuss with QI team feasibility of documenting staff time spent on tracking missing information by UNHSP and at the facility level)

Aim Statement 5:

Reduce the number of homebirths who did not receive hearing screening by 10% in the last quarter of 2014 by determining the timing of filing birth certificates and seek to improve early access to perform outreach to families

Changes/activities	Start date	Estimated completion	Staff partner	Process	Outcome
Work with Vital Records to determine process for collecting homebirth certificates and determine a testing mechanism in a	6/14	7/15	PC,CC, FOS, EPI,OS, LTFS, QIT, Vital Records Staff, Legal	Analyze data to determine city or town with significant number of home births and analyze timing of filing birth certificate, work with Registry of Vital Records to determine	Reduce number of infants who do not receive a hearing screen who are born at home by

city or town				if city/town has mechanism to file earlier	10%
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Plan: Meet with Vital Records and QI Team to discuss problem and review data, Do: Identify city or town to work with and present information about importance of hearing screening, Study: measure timing of filing of birth certificate information that is used by UNHSP for outreach, Act: Spread if improvements are noted/perform more PDSA cycles.

Aim Statement 6: Identify two additional audiological centers to submit data through informed consent who have registered for EHDI Pediatric Audiology List Serve, but are not a DPH approved ADC and are not currently submitting data to determine if they are testing young children who may be LTF/LTD.

Changes/activities	Start date	Estimated completion	Staff partner	Process	Outcome
Identify two centers currently not submitting data to determine willingness to submit data on infants/children and determine if it improves LTF/LTD	4/14	3/15	CC, FOS, QIT, EPI, OS, LTFS, DPH Legal Office	Work with DPH Legal Office to determine legal access to data and approach to collect data, Collect data for children through the six birthday, review current data and LTF/LTD from past years	Improve LTF/LTD and pending diagnosis, Implement with all centers who register for EHDI PALS

Plan: Work with DPH Legal Office, determine feasibility of collecting data from additional centers not part of current system, Do: Involve QI Team and identify two centers and provide data collection tools, collect data Study: Determine if data collected identifies past or current LTF/LTD infants/young children, Act: Identify additional centers to collect data.

Activities to ensure goals and objectives are achieved

Activity	Date	Staff Responsible
Hold UNHSP Advisory Committee Meetings	5/14, 10/14, 5/15, 10/15, 5/16, 10/16	PD, CC, All Staff
Hold Approved Audiological Assessment/Diagnostic Center Trainings; including an annual training combined with EI Program contacts	4/14, 9/14, 1/15, 4/15, 9/15, 1/16, 4/16, 9/16	PD, CC, OS
Hold Quarterly Meetings to discuss QI with other New England states and NY and discuss possible collaborative project on Border	4/14, 7/14, 10/14, 1/15 and	PD, CC, QIT, Staff, New England States and New York

Babies data	Ongoing	
Project Director meets with staff to review progress on data, goals, objectives, and activities	As needed and monthly	PD, All Staff
Continue to work on cross-training of staff and sustainability of system	Ongoing	PD, All Staff
Collect and analyze screening, diagnostic, and intervention data according to the national 1,3,6 objectives and perform outreach to identified families (see methodology for further information)	Ongoing	PD, All Staff
Evaluate progress, including proactively analyzing screening and diagnostic data and providing reports to facilities and monthly for QI Project	Quarterly	PD, EPI, All Staff
Target site visits to birth facilities and diagnostic centers based on program performance	Ongoing	CC, PD, EPI
Collect, review and approve Audiological Diagnostic Center Protocols for 30 currently approved DPH Audiological Diagnostic Centers	Ongoing	CC, PD, All Staff
Collect, review and approve Birth Facility protocols	Ongoing	CC, PD
Distribute UNHSP brochures to birth facilities (approx. 75,000 annually-13 languages) and UNHSP Parent Information Kits to providers and families in English and Spanish	Ongoing	OS
Continue to work with PELL Workgroup, including obtaining EI outcome data	Ongoing	PD, EPI, DPH Legal staff
Add New York to New England Border Babies Agreement	4/15-6/15	PD, New England states
Continue posting several times each week on active Facebook page and utilize other social marketing techniques (including regular e-mail blasts to families and providers)	Ongoing	CC, PD, FOS, OS
Continue to use Loss and Found Video and get final approval to disseminate digital story	Ongoing	PD, FOS, CC
Foster early literacy for deaf and hard of hearing children through all family support activities	Ongoing	CC, PD, OS

Holds QI Conference calls with team every two weeks and plan monthly meetings	Ongoing	PD, CC, FOS, QIT, Staff
Continue to monitor timeliness of screening information sent to UNHSP for transfer/NICU infants. Calculate time between screen and data received by UNHSP for all transfer/NICU infants. Analyze this data by facility. Address any delays in data reporting with facilities as needed.	Ongoing	EPI, PD, CC
Enter transmittal data and diagnostic data that is submitted on faxed paper forms	Ongoing	OS, CC
Send homebirth letters and educational materials to all families with an infant born at home in MA	Ongoing	OS, CC
Work with RVRS to educate birth facilities to update hearing screening results, risk indicators for transfer infants, and follow-up appointments in EBC as data indicates problems	Ongoing	PD, CC, OS, LTF
Collaborate with federal MCHB partners, other states as requested, and submit reports as requested	Ongoing	PD, CC, EPI
Continue to monitor use of scripts and training materials at hospital site visits and through protocol review, develop new scripts as needed, and update Outreach Documentation Manual	Ongoing	CC, PD
Distribute data reports to approved ADC's for data quality	Ongoing	EPI, OS
Follow-up with birth facilities and approved ADC's about missing or incorrect data	Ongoing	EPI, OS
Continue working on the EI sponsored "Partnering for the Success of Children with Hearing Loss Initiative" and collaborate on data collection	Ongoing	PD, FOS, CC, EI staff
Continue to provide technical assistance, support and education materials regarding early childhood screening for Head Start and Home Visiting Program and follow-up hearing screening for infants, participate in meetings and workgroups as requested,	Ongoing	CC, PD

including DPH Perinatal Workgroup		
Perform outreach to families whose preferred language is Spanish and continue to develop new educational materials in Spanish	Ongoing	LTFS, CC, PD
Utilize Language line for outreach to families whose preferred language is other than Spanish or English	Ongoing	All staff
Provide parent to parent support to every family at diagnosis, including later identified children through age six	Ongoing	FOS, CC
Analyze data to understand reasons why families become lost to follow-up and provide feedback to stakeholders, including families and Advisory Committee	Ongoing	EPI, PD
Run weekly reports of children who did not pass their screen and distribute to staff	Ongoing	CC, FOS, LTFS, EPI
Hold annual Parent Forum, regional support events and support families participating in program activities and outside support events as funding allows	Ongoing	CC, PD, Federation for Special Needs, Family TIES
Work with Family TIES to identify resources to train providers and staff in diverse cultural attitudes toward health	Ongoing	PD, CC, Family TIES, all Staff
Continue to update the Newborn Hearing Screening Program Documentation manual, including Childhood Hearing Data System and all policies	Ongoing	CC, PD, EPI, FOS
Provide training to local EI contacts, including e-mail blasts and webinars	Ongoing	CC, PD, EI staff
Evaluate satisfaction with all family activities and utilize surveys and focus groups as needed to obtain family input	Ongoing	CC, EPI, PD
Continue to work with AAP Champion on educational needs for primary care providers	Ongoing	PD, CC, Advisory Committee
Collaborate with AAP Champion on QI initiatives	Ongoing	PD, CC
Continue to work with MA Health and insurers on issues related to accessibility of appropriate pediatric audiology services, including implementation of recently passed	Ongoing	PD, CC

hearing aid law		
Continue working with the DPH Legal Office, DPH partners responsible for PELL access and continue to write updated justifications	Ongoing	EPI, PD, CC
Continue faxing primary care providers information on screening results for infants that are at risk of becoming LTF	Ongoing	LTFS, OS, FOS
Provide training to selected Title V funded Maternal, Infant, and Early Childhood Home Visiting Programs	Ongoing	PD, CC, Home Visiting Staff, Home Visiting Program
Identify facilities that have poor quality data submission and provide technical assistance (e.g., timely, incomplete, implausible)	Ongoing	EPI, CC, PD
Work with Medical Home initiatives through the CYSHN to ensure newborn hearing screening goals and objectives are understood	Ongoing	PD, CC
Participate on national workgroups and other activities at the national level	Ongoing	PD, CC
Continue collaboration with EI to collect and document need for data and verify effectiveness of the program through long-term outcome (including using PELL data	Ongoing	PD, EPI, CC, FOS
Attend EHDI Conference, submit abstracts, and present at conference	2014, 2015, 2016, 2017	PD, CC, Families, Advisory Committee members
Provide presentations to allied professionals and educational institutions	Ongoing	PD, FOS, CC, EPI
Continue to work with MA Commission for the Deaf and Hard of Hearing, Family Sign Language Program, EI Programs and Specialty Providers, MassHealth, CYSHN, and others to meet the needs of families	Ongoing	PD, CC, OS, FOS, LTFS
Enroll additional ADC in electronic reporting system	Ongoing	EPI, CC, PD
Provide technical assistance to other states and providers as requested	Ongoing	PD, CC, EPI

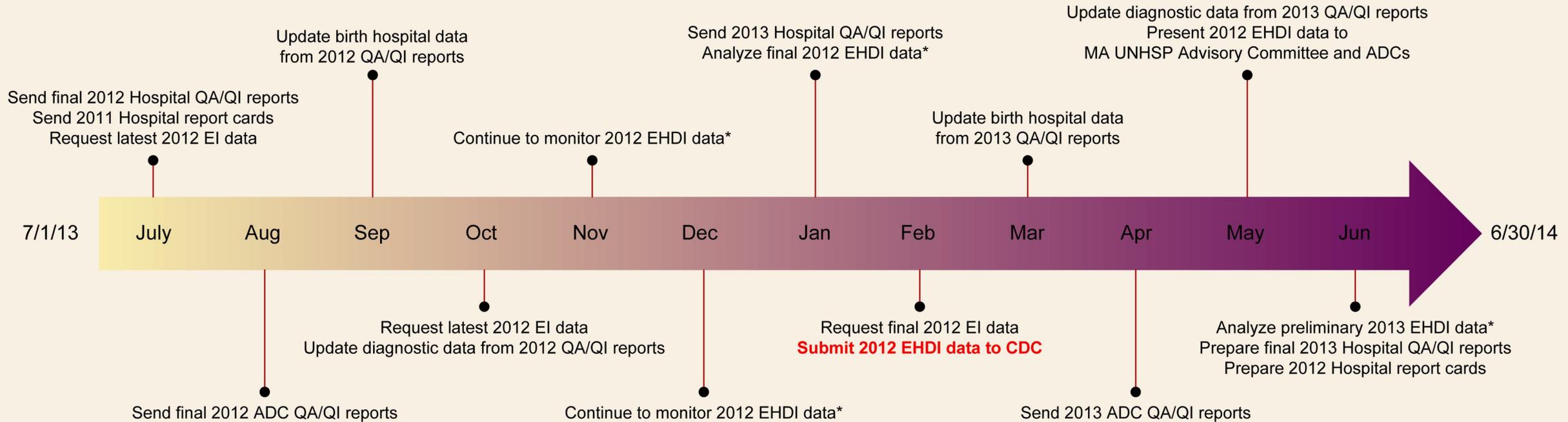
MA Attachment 4.2

Members of Quality Improvement Team

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2. Michelle Conlon, EI Regional Specialist, Early Intervention, Department of Public Health
3. Fifi Diop, Director, Office of Data Translation, Department of Public Health
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6. Sharon Pagnano, Director of Statistics, Registry of Vital Records and Statistics, Department of Public Health
7. Sarah Stone, Program and Communications Coordinator, Universal Newborn Hearing Screening Program, Department of Public Health
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Massachusetts Department of Public Health

Universal Newborn Hearing Screening Program QA/QI Timeline



* Disseminate child-specific lists to MA UNHSP outreach staff for:

1. Diagnostic lost to follow-up
2. Diagnosis pending
3. EI lost to follow-up

ADC – Audiologic Diagnostic Centers

CDC – Centers for Disease Control and Prevention

EHDI – Early Hearing Detection and Intervention

EI – Early Intervention

QA/QI – Quality assurance/quality improvement

MA UNHSP – Massachusetts Universal Newborn Hearing Screening Program

Massachusetts Accomplishment Summary during Project Period 4/2011-3/2014

Overall Goal:

The overall goal of this project was 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. (data finalized during the project period was 2009, 2010 and 2011)

Objective 1: Screen all newborns at birth or prior to one month of age

Infants Screened for Hearing Loss/Percentage Screened

Year	Screened for HL	Percentage Screened for HL
2009	74,835	99.5%
2010	72,698	99.6%
2011	72,914	99.5%

Infants Passed by One Month and Failed by One Month

Year	Passed Screen	% Passed by One month	Failed Screen	% failed by One Month
2009	72,622 (98.8%)	98.8%	1,311 (1.8%)	94.3%
2010	71,484 (98.3%)	98.8%	1,214 (1.7%)	94.6%
2011	71,550 (98.1%)	98.8%	1,364 (1.9%)	94.1%

Objective 1: Highlights of activities and quality improvement initiatives

- Distributed DPH Birth Facility Guidelines in January 2013 that included scripts for screeners, communication guidelines for families, risk indicator algorithm, hearing screening readmission tool and other parent materials. The Program Director and Communications Coordinator took the lead on this project and it was accomplished through family involvement in reviewing materials, workgroups with clinical providers that met over several months, Universal Newborn Hearing Screening Program Advisory input, testing materials through a small number of facilities prior to statewide implementation and final review and approval from Bureau and DPH Medical Director.
- Provided MA version of “Loss and Found, What to do if your baby didn’t pass the newborn hearing screening” to 50 birth facilities.
- Printed and distributed DPH UNHSP brochures to 50 facilities for each of the families of the 222,256 infants born during this period.
- Collected birth facility hearing screening protocols for 50 facilities for review and approval, including staffing forms for program director, audiologist involved in the screening program and birth data contact to improve communication with facilities.
- Developed standards to ensure that birth facilities make follow-up audiological appointments for all of the infants who failed newborn hearing screening prior to discharge and followed up with facilities when appointments were not made throughout the project period.

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 37th 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 \$2,000 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.

- Sent periodic reports to birth and audiological facilities to ensure data quality throughout the project period and distributed annual report cards to hospitals for 2009, 2010 and 2011 data during the project period.
- In the past, QI activities between birth hospitals and UNHSP were through confidential mailings or secure fax. UNHSP conducted a small test of change through the creation and electronic dissemination of QI Newborn hearing screening data reports for all infants born at a selected major birth hospital in Boston. Meetings were held with the birth hospital’s NHS audiologist, EHDI Chapter Champion and senior programmer analyst to develop strategies for the creation and electronic dissemination of quarterly QI NHS reports. The first report was sent out to the birth facility in 2013. The report contained child-specific information for all infants born at that facility, organized by NHS results: (1) pass (2) refer (3) not screened (by reason not screened). To ensure accurate linkage and to eliminate the possibility of duplicate data, the child-specific information on these reports included (1) birth hospital medical record number (2) infant’s date of birth (3) infant’s sex (4) infant’s full name (5) birth order, in the event of multiple births (6) mother’s full name. Based on these reports, the birth hospital will communicate any updates to UNHSP via electronic submission. Lessons learned from this small test of change will be applied to the creation and dissemination of any electronic QI NHS reports for birth hospitals statewide.
- Developed Quality Improvement Timeline for all data in July 2011
- Updated UNHSP Documentation Manual throughout the project period

Objective 2: Rule out or confirm hearing loss in infants who do not pass their newborn hearing screening by three months of age

Infants Lost to follow-up (LTF)

Year	Number Failed Screen	Number LTF	% LTF
2009	1,311	50	3.8%*
2010	1214	35	2.9%*
2011	1,364	41	3.0%*

*Does not include infants: who received audiological services and did not have a confirmed diagnosis, declined to provide information, deceased, moved

Objective 2: Highlights of activities and quality improvement initiatives

- Communications Coordinator and Program Director collected and approved 30 DPH approved audiological diagnostic center protocols and required birth facilities to refer to these centers.
- Provided trainings three times per year to the 30 DPH approved audiological diagnostic centers for a total of nine trainings and all staff were involved.
- Outreach staff made follow-up calls to all families whose infants did not pass during the project period (3,889 infants) and continued follow-up until the diagnosis was achieved.
- Outreach staff provided outreach calls in Spanish and English and used a translation line to ensure culturally sensitive and appropriate information.

- Outreach staff used fax-back with providers (e.g., copies of letters faxed to primary care when families did not go to appointments, contacted through fax and telephone pediatricians for infants at risk of becoming lost to follow-up).
- Outreach staff made appointment for families through three-way calling with the DPH approved audiological center.
- Epidemiologist and Outreach staff collected data through audiological tracking forms from DPH approved centers, including information on missed appointments and followed up with family or primary care.
- Documented through the birth certificate the name of the infant’s primary care provider and Outreach staff included the provider in follow-up when an infant was at risk of becoming lost to follow-up.
- Outreach staff used second point of contact through the electronic birth certificate (including father’s information) and recorded cell phone numbers for additional follow-up call).

Objective 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.

Year	Infants with Hearing Loss	% Enrolled in EI	% Enrolled by 6 months
2009	213	79.3%*	74.6%
2010	191	77.0%*	69.4%
2011	179	77.1%*	67.4%

*data indicates families with infants with unilateral, mild and conductive hearing loss were less likely to utilize EI services

Objective 3: Highlights of activities and quality improvement initiatives

- Outreach staff called all of the 583 infants diagnosed with hearing loss to provide support, technical assistance on public benefits and assisted families with enrollment in EI at the program level and using three-way calling between the facility, EI, and Family Outreach Specialist.
- Outreach Specialist provided Parent Information Kits in Spanish and English and translated numerous program materials for all of the 583 diagnosed with hearing loss and additional copies for providers.
- Program Director and staff collaborated with the Massachusetts Commission for the Deaf and Hard of Hearing through a Memorandum of Understanding to be certain families were connected to that agency for lifelong support and assistance.
- All staff collaborated with the EI Program and continued to update data use agreement to ensure infants with hearing loss are enrolled in EI and provided annual data back to EI each year.

Objective 4: Track infants and young children diagnosed with hearing loss through the sixth birthday and provide resources and supports to families.

Objective 4: Highlights of activities and quality improvement initiatives

- DPH Approved Audiological Diagnostic Center Guidelines require centers to submit data on children through the sixth birthday and this allows staff to analyze screening results for later identified children to determine if there was any way that diagnosis could have been achieved earlier and provides the program with information about how hearing loss can change over time. This will be used in future years for quality improvement and other data analysis.
- Support is offered to families with children later identified with hearing loss through the Family Outreach Specialist and he connects families to MCDHH.

Evaluation Projects

Evaluation projects using multiple data systems were carried out throughout the project period. The UNHSP analyzed data using SAS and other high level software. Legal access was granted to integrate data to the Pregnancy to Early Life Longitudinal Data System (PELL) and particular attention was paid to understanding disparities as they relate to cultural and linguistic minority populations and the needs of emerging populations in the state.

Evaluation Activities

- Program Director and Epidemiologist focused quality improvement strategies on data improvement, including birth and audiological facility data quality reports.
- Epidemiologist analyzed annual program hearing screening and follow-up data (including demographic, medical, risk-indicator for hearing loss) and staff presented it to the Advisory Committee, ADCs, conferences and other stakeholders.
- Epidemiologist analyzed barriers to care (e.g., racial/ethnic, geographic, diagnosis pending, LTF by mother's region of residence, LTF by maternal education) and provided information to outreach staff to be aware of barriers.
- Program Director and Epidemiologist analyzed risk indicator data for HL (used data to inform revised risk algorithm).
- Staff collaborated with Director of EI Specialty Services and collected EI data throughout the project period to determine referral and enrollment data.
- Program Director reviewed performance through data and targeted site visits and follow-up with birth facilities and ADCs when data was incomplete, missing, or erroneous.
- Communications Coordinator and Program Director created reports to measure number of calls and letters by staff person and by month/year and used these during employee review.
- Program Director provided reports and insight to DPH Senior Management on missing and implausible data throughout the implementation period of the new VIP birth certificate system.
- Staff provided technical assistance and support to birth facility and ADC staff by preparing facility specific and statewide data for presentations related to newborn hearing screening at various conferences.
- Epidemiologist analyzed data to begin to understand cochlear implants utilization and possible barriers/disparities for children across the state.

The following are two major evaluation projects that took place during the project period and the Epidemiologist, Program Director, Communications Coordinator and other staff were involved in the process.

Prevalence of Orofacial Clefts and Hearing Loss”

All infants born with orofacial clefts in 2004-2008 in MA were analyzed for access to audiologic diagnostic services and subsequent prevalence of hearing loss. Only 1:4 children with orofacial clefts received audiologic diagnostic services even though almost 80% of the children evaluated had confirmed hearing loss. These results were presented to the ADCs and the UNHSP Advisory Committee.

“Prevalence of Down Syndrome and Hearing Loss”

The UNHSP and PELL data systems were used to analyze data on Down Syndrome and Hearing Loss using five years of consecutive birth years 2004-2008 (most recent available complete years in PELL). Data was linked to obtain hospital discharge, emergency department, observational stay and mortality data. Prevalence of Down Syndrome, demographics and medical information was analyzed. Hearing loss was measured through UNHSP audiological reporting. Medical factors for infants with Down Syndrome included: 1) more likely to be born premature, higher infant mortality, 15 times more likely to refer on a hearing screen, bilateral refers are common, left ear referrals were twice as common as right ear referrals, age at screening was delayed for some infants. Of the infants that did not pass, two-thirds had some permanent hearing loss by the EHDI definitions. Hospital discharge data indicated children with Down Syndrome are most commonly admitted to the hospital with cardiovascular/heart disorder, respiratory infections, gastrointestinal disorders and other conditions. There was indication that there was possible underreporting of audiological data. Data was presented to Advisory Committee, Early Intervention Consortium Council and a resource sheet on Down Syndrome and Hearing Loss was developed.

Additional accomplishments of staff duties related to goals and objectives during the current project period 4/1/13-3/31/14 (data is estimated as current data was used to project through 3/14).

- Met with DPH leadership and project staff regularly to review workplan and carryout project goals, objectives, and activities.
- Convened UNHSP Advisory Committee meetings (June 13 and October 2013).
- Organized and held statewide DPH Approved Audiological Diagnostic Center meetings in 5/13 and 9/13 and held 1/14 webinar for ADCs.
- Held statewide family events: Amelia Park Children’s Museum 5/13, Boys and Girls Club Kidcasso 6/13, Family Conference call “Back to School, Tips from an Educational Audiologist with speaker Kym Myer, M.S., CCC-A from the Learning Center for the Deaf 9/13, Jam Time in Maynard (Big Joe the Storyteller)1/14.
- Provided assistance to five families to attend the Minuteman Cochlear Implant Conference in 7/13 and four families to attend the Clarke Mainstream Conference in 10/13.

- Staff continue to work with statewide Family TIES “together in enhancing support” program and currently 15 parents with children with hearing loss are trained to provide assistance statewide.
- Staff distributed 50 copies of “Gracie’s Ears” to families as part of an on-going literacy effort for infants and young children with hearing loss.
- Posted 551 times on Facebook page, engaged families and providers through 180 e-mail blasts, and used other social marketing techniques.
- Collected hearing screening data through the VIP system and DPH approved ADCs and entered data in the Childhood Hearing Data System (CHDS), monitored transfer data.
- Collected birth facility protocols for newborn hearing screening for review and approval in response to Hospital Guidelines that were revised and disseminated to 50 birth facilities in 1/13.
- Continued to review protocols and provide technical assistance to the 30 DPH ADCs
- Contacted homebirth families through information obtained through the VIP and sent 311 follow-up letters and information about where to go for testing.
- Provided support to >1,300 families prior to the follow-up appointment through 2,078 telephone calls encouraging them to attend the appointments, including reaching out to families in their preferred language and working to ensure payment for follow-up care when insurance was not available.
- Outreach Staff and Communications Coordinator sent letters to families in English and Spanish including: 568 to families whose infant did not pass the hearing screen, 138 letters to families whose infant missed the diagnostic appointment, 15 reminder letters about appointments, and 79 letters to families after diagnosis of hearing loss.
- Provided parent-to-parent support through a dedicated Family Outreach Specialist soon after diagnosis and recorded 479 outreach calls to families whose infant/young child was identified with hearing loss.
- Outreach Staff and Epidemiologist collected and entered diagnostic data from ADCs and made continuous systems improvements (e.g., more user friendly and improved functionality for data analysis).
- Lost to Follow-up Specialist faxed pediatricians about follow-up for NHS for families with infants who missed the first appointment or could not be reached by telephone
- Program Director, Communications Coordinator and Epidemiologist updated the systems documentation manual as part of a cross-training/sustainability plan and completed it on 10/13.
- Family Outreach Specialist took the lead with other program staff and developed a digital story for providers and families “Among Friends, A Labor and Delivery Nurses Experiences with Newborn Hearing Screening”.
- All staff collaborated with other early childhood programs to connect families to appropriate resources.
- Program Director and Associate Commissioner from the Massachusetts Commission for the Deaf and Hard of Hearing updated a Memorandum of Agreement that details how the two agencies will work closely to support families with children who are deaf and hard of hearing.

- Provided annual birth facility reports and “report cards” for 2011 data and audiological reports for data quality.
- Participated in EHDI PALS Workgroup and enrolled 30 centers into EHDI PALS (26 completed in EHDI PALS, 4 in progress (20 are DPH approved centers).
- Worked with Advisory Committee on amending birth facility risk indicator algorithm and tested the document with several large birthing facilities prior to disseminating the document statewide.
- In response to data that indicated children with mild and unilateral HL were less likely to enroll in EI, Family Outreach Specialist made targeted calls to educate families about the benefits of early intervention and worked with the statewide EI program to address this concern.
- Distributed 70,000 English, 12,000 Spanish, 1,000 Portuguese, 160 Haitian Creole, 20 Russian, 120 Arabic, 100 Hindi, 25 Khmer, 20 Korean, 580 Simplified Chinese (Mandarin), 50 Somali, 580 Traditional Chinese (Cantonese) and 600 Vietnamese program brochures to birth facilities
- Provided ADCs with 356 DPH Parent Information Kits (PIKs) that are provided at diagnosis in English and in Spanish.
- Collaborated with EI on the Partnering for Children with Hearing Loss initiative and disseminated information on Hearing Loss and Down Syndrome.
- Attended and presented at National EHDI Conference on “Audiological Services for Children with Oro-Facial Clefts in MA” and “Marketing, Messaging and Media: Massachusetts Family Outreach Plan”.
- Awarded Janet Farrell national Antonia Brancia Maxon award for EHDI Excellence in April 2013 and received MA Pride and Performance Award in May 2013.
- Submitted two abstracts that were accepted for presentation at the 2014 national EHDI conference, “Expect the Unexpected: EHDI Workforce Development and the Benefits of Cross Training and Succession Planning” and “Building an EHDI program that is Responsive to the Needs of Families”.
- Worked closely with CYSHN Management Team, DPH Director of Family Initiatives, Federation for Special Needs, representatives from the Deaf community and Massachusetts Commission for the Deaf and Hard of Hearing to ensure participation in the UNHSP Advisory Committee and identify families.
- Staff continued to work with MA Hearing Aids for Children Coalition and share information about the recently passed hearing aid statute with families and providers.
- Epidemiologist provided data to states that are part of the New England Border Babies Agreement and continued to provide technical assistance and support to other states.
- Program Directors and other staff participated in the MA Prevent Blindness workgroup for early childhood vision screening, Critical Congenital Heart Disease workgroup, Advisory Committees for Birth Defects, New England Genetics Collaborative and Newborn Screening.
- Program Director participated throughout the project period in the American Academy of Pediatrics Lost to Follow-up Workgroup and will be involved in a presentation on the accomplishments of the workgroup at the 4/14 EHDI Conference.

- Program Director and Communications Coordinator participate in monthly EHDI Chats and other national, regional, and local workgroups.
- Provided data to Beth Israel Deaconess Medical Center, Boston Children's Hospital, Brigham and Women's Hospital and other birth and ADCs for presentations.
- Program Director facilitated preliminary discussion on testing for cytomegalovirus between researcher from Children's Hospital Boston and New England Newborn Screening Program.