

Attachment 11 PDSA

Test of change #1

Start date: April 2014 **End date:** August 2014

Objective/aim:

Objective 1.2 Increase the OAE screening rates performed in home deliveries from 67% to 100% by March of 2015. (EHDI target: all infants screened by 1 month of age)

Area to work on:

Practice Change – Increasing home birth screening

Describe the change you are testing:

Currently, mothers who deliver their infants at home must either make an appointment for a screen at either a birthing hospital (requiring travel) or with a home visitor who brings along a screener (two unfamiliar individuals entering the home) to have a screen completed. The change we are testing is whether using trained midwives to screen decreases the number of infants born at home, who were not screened.

What do you predict the result will be?

Fewer infants, who were delivered at home, will miss an initial screening.

What questions does this test seek to answer (If I do x will y happen?)? What other questions about your theory do you have?

If midwives are trained to conduct OAE screens, will there be fewer home birth infants who do not receive an initial screening? Will midwives feel comfortable conducting hearing screens?

Plan for the test: who, what, when, where

From April-June 2014, midwives, after being trained from one midwifery practice will conduct OAE screens on those infants, delivered at home, who agree to a hearing screen. For those families who refuse a hearing screen, they will make sure that they receive a signed form that is transmitted to RIHAP.

Data collection plan to learn if the test is successful: who, what, when, where

At the beginning of August, the EHDI data manager will use the EHDI database to match home births with initial screening data. If the test is successful, all home births delivered by midwives in the test practice should either have a documented initial screening (in RIHAP) or a signed refusal form with the RIHAP follow-up coordinator.

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Test of Change #2

Start date: July 2014 **End date:** October 2014

Objective/aim:

Objective 2.1 Ensure that all infants who fail a newborn hearing screen receive appropriate evaluation by three months of age, reduce loss to follow up rates by 15% annually (EHDI target: ensure diagnosis by 3 months of age)

Area to work on:

Practice change – supporting primary care to support families

Describe the change you are testing:

Currently Parent Consultants placed in Primary Care offices use the Primary Care Provider report, which lists the practice's patients that need hearing follow-up. The Parent Consultants are not given specific guidance on how to follow up with the patients.

The change that we are testing: We will give a Parent Consultant specific guidance on how and when to follow up with patients.

What do you predict the result will be?

More families who have contact with the Parent Consultant will schedule and keep their follow-up appointments.

What questions does this test seek to answer (If I do x will y happen)? What other questions about your theory do you have?

If a parent consultant is given scripts and clear guidance on how and when to follow up with families who need hearing appointments, will more families both schedule and keep their needed appointments? Will parents be open to having a parent consultant help them schedule their appointments? Do families feel that the assistance of a parent consultant is helpful? Did the parent consultant find the guidance to be helpful?

Plan for the test: who, what, when, where

From July 2014 through September 2014, the parent consultant at 1 primary care practice will use the PCP report to work with families (scheduling and follow-up) who need a hearing screen, re-screen, diagnostic evaluation, and/or services. The parent consultant will use a script and clear guidance on how and when to work/follow-up with the families and will document all outreach done with the family.

Data collection plan to learn if the test is successful: who, what, when, where

At the beginning of October (quarter 3), when a new PCP report is generated (they are generated quarterly), the RIHAP coordinator will examine the quarter 3 PCP report and will compare it to the quarter 2 report to see if any of the families have moved off the list. The RIHAP coordinator will also look at documentation in KIDSNET and notes taken by the parent consultant; this will determine whether and which of the parent consultant's efforts were helpful in moving families through the hearing assessment process.

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Test of change #3

Start date: November 2014 **End date:** 20 families

Objective/aim:

Objective 2.1 Ensure that all infants who fail a newborn hearing screen receive appropriate evaluation by three months of age, reduce loss to follow up rates by 15% annually (EHDI target: ensure diagnosis by 3 months of age)

Area to work on:

Systems change – Use electronic reminders instead of paper

Describe the change you are testing:

Currently, screeners do not collect cell phone numbers; therefore, the EHDI Coordinator can not text families with at risk infants (in need of diagnostic evaluation because of risk factors) to remind them to schedule a diagnostic evaluation. To remind families to schedule a diagnostic evaluation at 6 months, the RIHAP Follow-up Coordinator mails letters to the families. Prior to this test of change, screeners will begin to collect cell phone numbers. Change we are testing: The RIHAP follow-up coordinator will use the cell phone numbers to send text messages to families reminding them to schedule a follow-up appointment.

What do you predict the result will be?

More families will schedule their recommended evaluation.

What questions does this test seek to answer (If I do x will y happen?)? What other questions about your theory do you have?

If families are reminded by text to schedule a diagnostic evaluation, will more families call to make an appointment?

Plan for the test: who, what, when, where

Baseline: Collect data on 20 families who were reminded through the mail to schedule their 6 month evaluation. Document how many families scheduled their appointment after being sent the reminder notice.

Test: The RIHAP Follow-up Coordinator will mail a letter to 20 families reminding them to schedule their 6 month evaluation. One month after sending the letters, send a text message to those families who have not yet scheduled their 6 month evaluation.

Data collection plan to learn if the test is successful: who, what, when, where

One week after sending the text messages reminding the families who have not yet scheduled their 6 month evaluation, the RIHAP Follow-up coordinator will use RITRACK to determine how many families have scheduled their evaluation. In addition, the RIHAP Follow-up coordinator will collect baseline data and test data to determine if more families who were texted scheduled an appointment versus families who just received a letter in the mail.

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Test of Change #4

Start date: April 2014 **End date:** August 2014

Objective/aim:

Objective 2.1 Ensure that all infants who fail a newborn hearing screen receive appropriate evaluation by three months of age, reduce loss to follow up rates by 15% annually (EHDI target: ensure diagnosis by 3 months of age)

Area to work on:

Practice/system change – Reduce loss to follow-up by collaborating with community partners

Describe the change you are testing:

Currently, formal collaboration with WIC offices does not exist even though some of the infants who are lost to follow-up are WIC clients. Change we are testing: Initiate formal collaboration with one WIC agency. The WIC agency will assist with providing families' contact information and scheduling hearing follow-up.

What do you predict the result will be?

A fewer number of infants needing hearing follow up will be lost to follow-up.

What questions does this test seek to answer (If I do x will y happen?)? What other questions about your theory do you have?

If WIC assists with follow-up, will fewer families be lost to follow up?

Plan for the test: who, what, when, where

The State EHDI Coordinator will use KIDSNET to identify if infants needing follow-up during Quarter 1 are in WIC. She will then give the WIC Parent Consultant the names of the infants in one WIC agency who need to schedule a rescreen or diagnostic evaluation. The WIC Parent Consultant will search in RIWebs (the WIC electronic database) for the infants' contact information; she will give the State EHDI Coordinator this contact information. If the contact information is different from that held by RIHAP or in KIDSNET, the State EHDI Coordinator will use the new contact information to contact the families and will offer to schedule an appointment at the next WIC visit. If the contact information is the same, the State EHDI Coordinator will coordinate with the client's WIC agency and ask the agency to schedule an appointment at the client's next WIC visit. All of this will be documented.

Data collection plan to learn if the test is successful: who, what, when, where

At the beginning of the next quarter, the RIHAP Follow-up Coordinator will use RITRACK to review the status of the children who needed follow-up during the previous quarter to see if they have either scheduled or received follow-up. She will also look at the documentation of who was contacted and compare that to who has scheduled or received follow-up.

If the test is successful, some of the children who needed follow-up and were contacted by either the State EHDI Coordinator or the WIC Agency, will either be scheduled or have received a follow-up appointment.

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Test of change #5

Start date: January 2015 **End date:** April 2015

Objective/aim:

Objective 3.1 Increase the number of completed initial hearing screens, re-screens and audiological evaluations documented in RI-EHDI data system to reach 100% by March 2015.

Area to work on:

System change – reducing LTF/D through better information sharing

Describe the change you are testing:

Currently, Audiologists submit a claim to Medicaid on completed diagnostic evaluations. Medicaid data is not linked with KIDSNET data, therefore if an Audiologist does not report completing an evaluation in KIDSNET as well, RIHAP does not know that the evaluation was completed.

Change:

Link Medicaid data with KIDSNET data.

What do you predict the result will be?

Children who were assumed to be either lost to follow-up or in process will no longer fall in either category and instead will have been lost to documentation.

What questions does this test seek to answer (If I do x will y happen?)? What other questions about your theory do you have?

If Medicaid data is linked to KIDSNET data, will RIHAP identify children who have been falling in the lost to follow-up category but have actually been seen or diagnosed by an audiologist?

Plan for the test: who, what, when, where

During Quarter 4, the KIDSNET Data Manager will provide a Medicaid Data Specialist with a list of infants from that quarter who are in both the follow-up or in process categories. The Medicaid Data Specialist will look in the Medicaid Data system for documentation of an audiological examination and/or diagnosis and will provide that information to the KIDSNET Data Manager.

Data collection plan to learn if the test is successful: who, what, when, where

During the same quarter (4), The KIDSNET Data Manager will look at the information provided by the Medicaid Data Specialist to determine if any of the children on her list had Medicaid documentation of hearing follow-up. If Medicaid has documentation that RIHAP does not have, the test was successful.

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Test of change #6

Start date: January 2015 **End date:** April 2015

Objective/aim:

Objective 3.1 Increase the number of completed initial hearing screens, re-screens and audiological evaluations documented in RI-EHDI data system to reach 100% by March 2015.

Area to work on:

Practice change – reduce LTF/D through better documentation

Describe the change you are testing:

Currently, a KIDSNET staff member does a one-time training with Audiologists on how to complete diagnostic evaluations.

Change:

Supplement training offered by a KIDSNET staff member by providing Audiologists with “Articulate Storyline,” e-learning software that includes information about how Audiologists can document their diagnostic evaluations.

What do you predict the result will be?

Audiologists will use Articulate Storyline e-learning software to assist them with questions about documentation and documentation will increase.

What questions does this test seek to answer (If I do x will y happen?)? What other questions about your theory do you have?

If Audiologists have access to Articulate Storyline, will they use it, and then, in turn will their documentation increase?

Plan for the test: who, what, when, where

The RIHAP Administrative Audiologist will train one practice of audiologists, who have already received the initial KIDSNET training, on how to use Articulate Storyline. The audiologists will be instructed to use Articulate Storyline from January- March 2015 for any questions that arise while documenting.

Data collection plan to learn if the test is successful: who, what, when, where

During the quarter that the test practice is using the Articulate Storyline software, the EHDI Data Manager will track the number of times the audiologists access the e-learning software. At the beginning of April, the RIHAP Follow-up Coordinator will look to see if there is a corresponding increase between accessing the Articulate Storyline software and documentation.

Attachment 1: Work Plan

Work Plan

Activities related to the following goals and objectives will be implemented to achieve the activities proposed in the methodology section:

Goal 1: Increase the number of infants who receive an initial hearing screen by 1 month of age, and ensure that screening results are documented.

*Objective 1.1 Evaluate screening and documentation at birthing hospitals to ensure that 100% of infants are screened and have documentation of screening by 1 month of age.
(EHDI target: all infant screened by 1 month of age)*

Strategy/Activity	Staff	Outputs	Timeline
Compile and review data on children who did not receive an initial screen by 1 month of age.	RIHAP Audiologist EHDI Coordinator EHDI Data Manager QI Team	Results reported to Rhode Island EHDI Program and QI Team	June 2014-ongoing
Develop and Implement PDSA	RIHAP Audiologist EHDI Coordinator EHDI Data Manager Birthing Hospitals	PDSA are developed and implemented	June 2014-ongoing as needed

RIHAP =Rhode Island Hearing Assessment Program, EHDI = Early Hearing Detection and Intervention
QI = Quality Improvement

Objective 1.2: Increase the OAE screening rates performed in home deliveries from 67% to 100% by March of 2015. (EHDI target: all infant screened by 1 month of age)

Strategy/Activity # 1 (Test of Change Activity #1)	Staff	Outputs	Timeline
Re-educate midwives about Newborn Hearing EHDI system.	RIHAP Audiologist EHDI Coordinator	Educated Midwives	April 2014-ongoing
Train midwives attending home births to perform and report OAE screening. (Test of Change Activity #1)	RIHAP Audiologist EHDI Coordinator Mid wives	Trained Midwives	May 2014-ongoing as needed
Train midwives to obtain signed refusal forms from families refusing a hearing screen. (Test of Change Activity #1)	RIHAP Audiologist EHDI Coordinator	Obtain signed refusal forms	May 2014

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Evaluate home birth screening process.	RIHAP Audiologist EHDI Coordinator	Satisfaction survey completed with identified midwives	July 2014
Monitor screening rates reported to EHDI data system	EHDI Data Manager EHDI Coordinator	Baseline report and ongoing screening reports	2014-ongoing quarterly

RIHAP =Rhode Island Hearing Assessment Program, EHDI = Early Hearing Detection and Intervention
 QI=Quality Improvement

Objective 1.3: Ensure 100% of newborn hearing screens are documented in KIDSNET (EHDI target: all infant screened by 1 month of age)

Strategy/Activity	Staff	Outputs	Timeline
Review data and documentation on “transferred out of state” infants.	EHDI Coordinator EHDI Data Manager	Results reported to Rhode Island EHDI Program and CQI Team	April- 2014-ongoing
Review current process for those infants “transferred out of state” without documentation of an initial hearing screening.	EHDI Coordinator EHDI Advisory Council Birthing Hospitals	Results reported to Rhode Island EHDI Program and QI Team	April- 2014-ongoing
Modify current interstate data sharing agreement.	EHDI Coordinator State EHDI Coordinators	Modified interstate data sharing agreement	May - 2014
Host regional conference calls	EHDI Coordinator State EHDI Coordinators Regional Officer RIHAP Staff	Regional QI best practices shared	September 2014-quarterly

RIHAP =Rhode Island Hearing Assessment Program, EHDI = Early Hearing Detection and Intervention
 QI=Quality Improvement

Attachment 1: Work Plan

Goal 2: Reduce loss to follow-up after a failed newborn hearing screen

Objective 2.1 Ensure that all children who fail a newborn hearing screen receive appropriate evaluation by three months of age, reduce loss to follow up rates by 15% annually (EHDI target: ensure diagnosis by 3 months of age)

Strategy/Activity #1 <i>(Test of Change Activity # 2)</i>	Staff	Outputs	Timeline
Work with primary care providers to review PCP report. Parent Consultant will assist PCP offices to support families who are in need of a re-screen, diagnostic evaluation and or services.	EHDI Coordinator Parent Consultant PCP Offices	Screenings or audiological visits reported to EHDI-IS	July 2014-ongoing
EHDI Coordinator, Parent Consultant and Advisory Committee will develop a script/guide.	EHDI Coordinator Parent Consultant	Script/guide developed	July 2014 – ongoing
Strategy/Activity #2			
Develop and implement on-line demographic form to capture alternate information, email, cell phone and best time/day to contact families.	RHIAP Audiologist EHDI Coordinator EHDI Data Manager	Alternate information available in RITRACK	August 2014 – ongoing
Implement a system to allow text reminders to families with a scheduled follow-up appointment. <i>(Test of Change Activity # 3)</i>	RIHAP Audiologist EHDI Data Manager	Follow-up appointments completed	November 2014-ongoing
Strategy/Activity # 3 <i>(Test of Change Activity # 4)</i>			
Identify children who are “lost to follow-up” and are in WIC Program and who have not received a diagnosis by 3 months.	EHDI Coordinator RIHAP Coordinator WIC Parent Consultant QI Team	Follow-up completed	April 2014 - March 2016
Train Parent Consultant and HEALTH WIC staff in test of change activity # 4	EHDI Coordinator WIC Parent Consultant QI Team	Staff trained	April 2014 - March 2016
Collect and evaluate data	EHDI Coordinator RIHAP Coordinator QI Team	Data collected and evaluated	April 2014 - March 2016
Implement WIC/EHDI policy and procedure for children “lost to follow-up”	EHDI Coordinator RIHAP Coordinator Advisory	Policy and Procedure developed and implemented	April 2014 - March 2016

Attachment 1: Work Plan

	Committee	
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RIHAP =Rhode Island Hearing Assessment Program, PCP= Primary Care Provider; MIECHV= Maternal Infant, Early Childhood, Home Visiting Program

Goal 3: Improve documentation after a failed Hearing Screening regarding audiological evaluation and engagement in services

Objective 3.1 Increase the number of completed initial hearing screens, re-screens and audiological evaluations documented in RI-EHDI data system to reach 100% by March 2015.

Strategy/Activity #1	Staff	Outputs	Timeline
Provide incentive webinars to audiology practices to reinforce the importance of documenting audiological evaluations into EHDI system.	RIHAP Audiologist EHDI Coordinator	Diagnostic evaluation results are entered into KIDSNET	April 2015 January 2016
Strategy/Activity # 2 (Test of Change # 5)	Staff	Output	Timeline
Access and develop report from Medicaid data system to identify audiology claims submitted for payments	KIDSNET Manager EHDI Coordinator	Audiologist is identified	January 2015-ongoing
Strategy/Activity # 3 (Test of Change # 6)	Staff	Output	Timeline
Develop Articulate Storyline e-learning.	EHDI Coordinator EHDI Data Manager	Articulate Storyline e-learning developed	January 2015-ongoing
Implement Articulate Storyline e-learning	EHDI Coordinator EHDI Data Manager	Articulate Storyline e-learning developed	January 2015-ongoing

RIHAP =Rhode Island Assessment Program, Mgt. =Management Team , UNHS= Universal Newborn Hearing Screening, QI=Quality Team

Objective 3.2 Improve documentation of engagement in services by 6 months of age for children who are diagnosed with hearing lost. (EHDI target engagement in services by 6 months)

Strategy/Activity # 1	Staff	Outputs	Timeline
Collect and analyze data on all children identified with hearing loss	EHDI Coordinator Part C Director/ EHDI Data Manager	Data collected and analyzed	April 2014 - ongoing
Coordinate with Part C Early Intervention Program to ensure that all children with identified hearing loss are enrolled and have an IFSP date documented in KIDSNET.	EHDI Coordinator Part C Director/ EHDI Data Manager	Children identified with hearing loss are enrolled in EI	April 2014 - ongoing

RIHAP =Rhode Island Hearing Assessment Program, PCP= Primary Care Provider; MIECHV= Maternal Infant, Early Childhood, Home Visiting Program ,QI=Quality Improvement

Attachment 1: Work Plan

Goal 4: Increase the number of rescreens/audiological evaluation for children who passed the initial newborn hearing screen but have risk factors for later hearing loss.

Objective 4.1: Increase by 50% the number of children who had completed diagnostic evaluations by six months of age if they passed their initial hearing screen but had risk factors for hearing loss.

(EHDI target all children diagnosed by 6 months)

Strategy/Activity # 1	Staff	Outputs	Timeline
Evaluate and revise current education and outreach efforts to parents with children "at-risk" for hearing loss.	RIHAP Audiologist EHDI Coordinator Parent Consultant CQI Team	Education and Outreach efforts revised	June 2014-ongoing
Strategy/Activity # 2	Staff	Outputs	Timeline
Using RITRACK/KIDSNET evaluate/identify the number of children "at-risk" for hearing loss and determine the number enrolled in early childhood programs such as Early Intervention, Early Head Start, and MIECHV.	RIHAP Audiologist EHDI Coordinator EHDI Data Manager CQI Team	Data collected	September 2014-ongoing
Develop a PDSA that, to improve the rates at which families get rescreened or schedule audiological evaluations.	RIHAP Audiologist EHDI Coordinator EHDI Data Manager CQI Team	PDSA developed	October 2014
Evaluate developed PDSA	RIHAP Audiologist EHDI Coordinator EHDI Data Manager CQI Team	PDSA evaluated	November-December 2014
Expand collaborations and coordination with early childhood programs Early Head Start, MIECHV and Childcare providers.	EHDI Coordinator Early Childhood Providers	Early Childhood collaboration and collaborations expanded Decrease number of "at risk" children lost to follow up	January 2015-ongoing

Introduction

Rhode Island has a longstanding commitment to ensuring that hearing loss in newborns is detected and treated at the earliest possible point. Early detection and follow up is the best way to ensure that children with hearing loss have the opportunity to reach their full potential. The Rhode Island Department of Health (HEALTH) has worked for decades to develop and maintain a high quality system of newborn hearing screening and follow-up based on the understanding that early support for children and their families plays a significant role in mitigating negative outcomes that can be associated with hearing loss. Furthermore, the National Center for Hearing Assessment & Management (NCHAM) reports that detection and treatment for hearing loss at birth for one child saves \$400,000 in special education costs by the time the child graduates from high school. Early detection of hearing loss is essential to both individual and community outcomes.

Centers for Disease Control & Prevention (CDC) studies demonstrate that hearing screening rates among states with universal newborn screening legislation are significantly higher than rates in states without legislation.¹ Rhode Island and Hawaii were early adopters of this approach and were among the first states to pass universal newborn hearing screening legislation in the early 1990s. Following the passage of legislation that required all newborns be screened for hearing, universal newborn hearing screening was implemented in all birthing hospitals in the state. Since the implementation in 1994, RI has had high rates of newborn hearing screening consistently exceeding 99.8%. Contributing to RI's high rate of screening is the fact that newborn hearing screening is a covered benefit reimbursable by all health insurers, and RI has high rates of infants who are insured at birth.² National Health Care Reform under the Affordable Care Act will provide Rhode Island with even more opportunities to expand access to health care coverage for uninsured children.

Follow-up has always been an essential component of the RI's Early Hearing Detection and Intervention program (RI EHDI). For the past decade, RI EHDI has focused on infants that could potentially be lost to follow-up, including infants who were not screened prior to hospital discharge and infants who failed to pass the newborn hearing screen and did not receive the appropriate follow-up or did not have documentation of appropriate follow-up. Since 2011, hearing screening and follow-up, supported by HRSA funds, has focused on reducing loss to follow-up with a goal of completing follow-up for all infants. As a result, RI-EHDI activities implemented between 2011 and 2013 focused on the following: 1) Implementing new outreach and screening efforts that include home visiting programs; 2) Establishing partnerships with Early Head Start programs; 3) Building systems to ensure that infants with risk factors for hearing loss receive appropriate follow-up; 4) Developing standardized language testing and reporting protocols of receptive and expressive language milestones for all Part C Early Intervention programs to ensure children are enrolled in services and receive appropriate services. To further support excellence in screening and follow up, in 2007, RI EHDI adopted the Joint Committee on Infant Hearing (JCIH) position statement, *Principles and Guidelines for*

¹ Green, DR, Gaffney, M, Devine, O, Grosse, SD (U.S. Centers for Disease Control & Prevention). Public Health Reports, March-April 2007, Volume 122, 198-205.

² Rhode Island Department of Health, KIDSNET.

Early Hearing Detection and Intervention Programs, which focuses on assuring that activities related to eight principles, are incorporated within a state's EHDI system.³

RI-EHDI is a collaborative effort by design. RI-EHDI partners' include Maternal and Child Health and Children with Special Health Care Needs programs at HEALTH. Other participating agencies include the Commission for the Deaf and Hard of Hearing, the birthing hospitals, primary care and specialty providers, audiologists, the Part C Early Intervention Program, RI School for the Deaf, otolaryngologists, geneticists, parent consultants, and families. These key partners collaborate with HEALTH to develop hearing screening systems, programs, and tools for follow-up, intervention, quality assurance, and evaluation to ensure successful outcomes for RI EHDI.

The overarching goal of the proposed project is to reduce the number of infants lost to follow up after failure to pass a newborn hearing screen. Within this important goal RI will implement objectives and engage in quality improvement activities to achieve the federal EHDI targets of hearing screening by 1 month of age, diagnosis by 3 months of age, and intervention by 6 months of age. By April 2017, the Rhode Island EHDI Program will achieve:

- 99% or more of newborns are documented to have received an initial hearing screening by one month of age
- 90% or more of infants who do not pass their initial screen are documented to have an audiological evaluation by three months of age
- 85% of infants who have a diagnosed permanent hearing loss are enrolled in EI with documentation of enrollment by six months of age

The goals, objectives and activities proposed in this application will allow Rhode Island to sustain and improve its successful universal newborn hearing screening and follow up efforts conducted over the past 3 years (Attachment 7), by continuing to focus on ensuring that all infants born in the state of Rhode Island are screened for hearing and receive appropriate follow-up. Continued support through this funding opportunity will also allow RI-EHDI to use quality improvement efforts to work both within HEALTH as well as with partners to improve outcomes. This funding will also allow RI to address screening a particularly hard-to reach population – infants who are born at home.

Needs Assessment

Rhode Island is a small, largely urban state with a total population of slightly over 1 million. Much of the population is concentrated in the central part of the state, which has the largest and most densely populated cities including Providence, Pawtucket, Central Falls, Cranston and Warwick. The largest number of health care providers and other social service providers are also located in these areas. These areas of the state are the most ethnically and culturally diverse and also have the highest concentration of families that face risk factors for poor outcomes, including poverty, low levels of education, high rates of maternal depression, and young single parents. Families that live in the southern end of the state have less access to health services, particularly specialty services, including audiology. There are seven birthing hospitals in RI, located throughout the state, but by far the largest percentage of births (75%)

³ Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics*, 2007, 120, 898-92

occur at Women and Infants Hospital, which is the regional perinatal tertiary care center located in Providence, the largest city in RI. A new change in RI is the small, but increasing number of families who are choosing home births; in 2012, 24 infants were born at home.

The target population for this grant includes four primary groups of infants and their families: 1) Infants who do not receive a newborn hearing screen by time of discharge from the hospital or by 1 month of age; 2) Infants who fail a newborn hearing screen and do not receive diagnosis by 3 months of age; 3) Infants who are diagnosed but are not enrolled in services by 6 months of age; 4) Infants who pass the newborn hearing screen but have risk factors for later hearing loss.

Of the 11,652 infants born in 2012, 11,580 received a hearing screen (Attachment 6.1). Of the 72 infants who were not screened, 62 died and 10 have no documentation of an initial hearing screen and are considered lost to follow-up. In 2012, of the total number of infants screened, 11,463 infants passed an initial screen, however 1.7% (193) of these were screened outside the recommended one month time frame. In 2012, 117 infants failed an initial screen; 24.8% (29) of these were screened outside the recommended time frame. Therefore, RI has 10 infants on whom there is no information and 222 infants who were screened outside of the recommended one month time frame.

Of the 117 infants who completed and failed their initial screen, 56 passed the audiological evaluation, but 13 of these (23%) were completed outside the recommended 3 month target. Fifty-one of the infants did not have a conclusive diagnosis by 3 months; 29 of these were considered to be “in process.” An infant is considered to be “in process” if she has seen an audiologist (or other qualified provider) at least one time by 3 months and has a follow-up appointment already scheduled. These infants are not considered lost to follow up since they are engaged with a provider, but it is of concern that there was no conclusive diagnosis within the 3 month time frame. RI will examine whether there are legitimate reasons that there is no diagnosis within the 3 month time frame. For 22 of the infants there is no information at all (considered lost to follow-up). A portion of these 22 infants may have received recommended follow-up, however the state did not receive documentation of follow-up. Nine infants were diagnosed with hearing loss; of these 3 were not diagnosed by 3 months of age. RI has small numbers of infants who are not engaged in services by six months; in 2012 there were three.

The numbers described above include 24 home births. Infants born at home are screened at much lower rates than infants born in hospitals; 58% compared to 99.4%. Of the 24 infants who were born at home, 10 did not receive a newborn hearing screen; the state has no documentation on these infants related to hearing screening. These infants are included in RI’s lost to follow-up population. In RI home births are a small population. However, if the home birth population has health needs that are related to hearing loss or to another health condition, and if these health needs go unmet, this is a significant issue. In addition, the number of home births has been slowly but steadily increasing.

In 2012, RI had 32 infants (10 who were not screened and 22 who were lost to follow-up after failing an initial screen) on which there was no current information about their hearing status. A high proportion (60%) of the 32 infants considered lost to follow-up were born in the southern part of the state, which is geographically the furthest distance from pediatric audiology services; furthermore few audiologists in that area routinely report results to RI EHDI. Securing other health services in this area of the state is more challenging than in more urban areas of the

state. This may put infants with hearing loss or who have not been screened, at risk for being unable to secure needed services.

There are some differences between the health characteristics of the overall population (Attachment 6.2a) and the health characteristics of the lost to follow population, which are characterized in Attachment 6.2b. Overall, most infants born in RI are born in urban areas (over 90%), English is the language most often reported as being spoken at home (92%), nearly half of the mothers report educational attainment beyond high-school, and 44% report being single parents. Nearly half (46%) of the infants born in 2012 were on public insurance and 31% received a home visit. Sixty three percent of infants born in 2012 were “risk positive” This status is created by an algorithm based on a developmental profile done at birth on all families of infants born in RI (Attachment 8). Risk positive means that the families of infants, or the infants themselves, have two or more risk factors for negative health outcomes. Compared to the target populations for this proposal, a low proportion (9%) of the general population spent time in the Neonatal Intensive Care Unit (NICU).

The health characteristics of infants lost to follow up, and their families, are diverse and include some evident potential health disparities. Slightly over 30% of the families of these infants reported speaking Spanish as their primary language. Overall the parents of these infants had lower levels of education, with less than 30% reporting progressing beyond a high school education, which might impact the ability of a family to get services. Also of significance, 30% of the mothers reported poor maternal mental health, which may also impact their capacity to ensure that their infants received needed services. Interestingly a lower proportion of infants in this group, 38% compared to 46% in the overall group, were reported as being on public insurance. Many of the mothers (40%) of these infants were single; it is likely more challenging as a single parent to take your child to follow-up appointments, particularly if you have more than one child. Over 50% of the infants in the lost to follow-up group were “risk positive”. Families who face multiple risk factors likely have additional challenges in supporting their children to get services. A low percentage (16%) of the infants in the lost to follow-up group received a home visit. Due to the individual health characteristics of this population, interventions will need to be tailored to different groups. It is likely that the strategies developed for families who experience multiple risk factors will need to be more intensive than those developed for families who experience less risk for poor outcomes.

The health characteristics of the 238 infants on whom RI has information, but fall outside of the EHDI targets, are somewhat different than the lost to follow-up infants (Attachment 6.2c). Seventy five percent of these infants were born in the urban core (179), a high percentage (73%) spent time in the NICU, and a high proportion were risk positive (91%). These factors likely played a significant role in the infants not receiving services within the EHDI time frames. In the first quarter of 2014, RI EHDI will examine how significantly NICU status is impacting time frames. In spite of a high population of risk positive infants, only 37% received a home visit. RI EHDI will need to determine why the rate of home visiting is so low. Nearly half (45%) of mothers reported that they attended some college and most (88%) reported English as the language spoken at home. Similar to the other target populations, many (48%) reported public insurance. All of these factors, must be considered as RI EHDI develops strategies to better reach the 1,3,6 EHDI targets.

Although, in 2012, there were only 9 infants with a diagnosed permanent hearing loss, Rhode Island fell short of the goal that 75% of these infants are documented to have an IFSP date by 6 months of age. Of the 9, 1 died, 1 moved out of state, and only 4 of the remaining 7 infants, or 57%, were enrolled in Early Intervention (EI) by 6 months of age. Two potential reasons why a child might not receive EI by 6 months of age include: 1) The infant, along with a hearing loss diagnosis, is also medically involved with a life threatening condition(s); 2) The family delays involvement with EI due to either denial of the hearing loss diagnosis or for other reasons until after the 6 month benchmark.

Finally, in 2012, of the 11,580 infants screened, 931 (8%) had a known risk factor for hearing loss; 883 (94%) of the 931 passed the newborn hearing screen, but remained at increased risk for hearing loss. Only 221(25%) of this group of 883 infants had an audiology diagnostic assessment completed by 6 months of age. At the current time RI cannot determine the health characteristics of those who got an audiology appointment compared those who did not. However, characteristics of the 883 are presented in Attachment 6.2d. Unlike the lost to follow-up group, a low percentage of the infants were born in the Southern part of the state (2.5%). A significant number 691 (78%) spent time in the NICU. There are a number of risk factors for hearing loss that are related to infants spending time in the NICU; the overall health status of this group of infants is likely to be worse than that of the lost to follow-up population and will need to be considered in any strategies developed to ensure that these infants get recommended follow up. Approximately 50% of the at risk infants were on public insurance, which is similar to the infants in the lost to follow-up group. A significant percentage (45%) of the mothers of these infants reported being single parents, nearly 40% reported that they did not have beyond a high school education and 91% (802) were considered risk positive at the time of the child's birth. NICU stay greater than 48 hours will result in a 'risk positive' status. So for at least 691 of the infants who had NICU stays, this may have been the contributing factor to the risk positive status. In 2014 RI EHDI will explore this data in greater detail as it develops strategies to engage with these families. Although 802 infants were risk positive, only 330 received a home visit. RI will need to explore the reasons for this low rate of home visits for a population that is clearly eligible; as previously mentioned, it this may be related to extended NICU stays among these infants.

In RI there are two primary information collection systems, KIDSNET and RITRACK, that support tracking of hearing screening. While KIDSNET and RITRACK are excellent and comprehensive systems, sometimes reporting in the systems is problematic and can cause an infant to appear lost to follow-up. For instance, audiologists do not consistently report on their diagnostic appointments. A 2012 KIDSNET audiology report revealed 29 unique audiologists reporting to RI-EHDI. Of those 29 audiologists, there were 1,720 total actual visits for an audiological evaluation reported. In 2011, 32 audiologists reported 2,067 actual visits. This most likely reflects a decrease in reporting. Change strategies have been proposed in the work plan to provide meaningful education to audiologists and to engage them, including providing on-line trainings, webinars and feedback reports with the end goal of stressing the importance of reporting audiological evaluations to RI-EHDI.

Efforts to reduce loss to follow-up will focus in the following areas: 1) Ensure that all infants, born at both the hospital and at home, receive an initial screen within the recommended time frame; 2) Outreach to families whose infants fail an initial screen to help them understand

the importance of addressing hearing loss; 3) Collaborate with audiologists and related professionals and with providers who see infants to ensure that hearing screening is tracked, diagnoses are captured, and families are appropriately followed; 4) Improve reporting of results into state data systems.

RI will also use a continuous quality improvement plan to address the population of infants who pass initial hearing screens but who have risk factors for hearing loss. While this population of infants and young children has been challenging to engage in services, it is critical to their later success that they receive appropriate intervention at the earliest possible point, and that hearing loss does not go undetected. The Joint Commission on Infant Hearing (JCIH) 2007 Position Statement recommended the following: “The timing and number of hearing re-evaluations for children with risk factors should be customized and individualized depending on the relative likelihood of a subsequent delayed-onset hearing loss.”⁴ Addressing this recommendation is critical since the rate of hearing loss increases from 2/1000 at birth to 5/1000 by 5 years of age. RI-EHDI recommends screening every six months for infants with risk factors.

There are programmatic and systems-level barriers that RI will need to address to achieve the 5% decrease in loss to follow up annually. Convincing families of infants with risk factors to complete recommended audiology assessments remains a major challenge. Lack of compliance results in missed opportunities to identify and provide intervention for hearing loss. Therefore an important initiative of this proposal is to identify and implement novel outreach approaches for participation in the EHDI process. RI-EHDI recognizes that timely follow-up is essential not only for infants who fail the newborn screen but also for infants who pass the screen but have a risk factor for hearing loss. It is imperative that providers support those families whose infants have hearing loss so that they receive both a conclusive diagnosis and appropriate and indicated early intervention services as early as possible.

Rhode Island shares borders with Massachusetts and Connecticut. An established data sharing agreement with other New England states permits exchange of information regarding infants born or tested in other states. The agreement is currently signed by four of the six states (Rhode Island, Massachusetts, Vermont, and Maine). During the process of gathering information from Border States and performing case reviews, it became clear that the agreement was limited because it only applies to infants residing in the other states. RI will modify the current border agreement in order to collect data from other EHDI programs regarding all Rhode Island born infants in need of follow-up, regardless of their state of residence.

An ongoing priority is to work with audiologists to learn about the infants receiving services and to make sure that infants are not considered lost to follow-up due to lack of documentation. Although there are many efforts in place to reduce loss to follow-up, this continues to be a challenge for the state. Rhode Island has gathered extensive information about the characteristics of families whose infants become lost to follow-up and is ready to implement systematic and programmatic changes to address these barriers. Distinct quality improvement activities and interventions to reduce loss to follow-up are described in detail in the Methodology

⁴ Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing

⁴ Detection and Intervention Programs. *Pediatrics*, 2007, 120, 898-921

and Work Plan sections of this narrative along with a Plan/Do/Study/Act cycle (PDSA) for each objective/aim proposed.

Methodology

The overarching goal, or aim, of this project is to reduce the loss to follow-up/documentation (LTF/D) of infants who have not passed a newborn hearing screen prior to discharge from the newborn nursery, and to ensure infants in RI receive services within the recommended EHDI timeframes. RI will accomplish this goal by developing and implementing focused efforts, including continuous quality improvement, in a variety of different settings and with different types of providers. RI's goal is to reduce loss to follow-up by at least 5% per year between 2014-2017. Specific goals and objectives were developed to help RI reach this overarching goal and further support RI to achieve the federal EHDI targets of hearing screening by 1 month of age, diagnosis by 3 months of age, and intervention by 6 months of age.

RI's specific targets that will be achieved, consistent with national EHDI goals, by April 2017 are:

- 99% or more of newborns are documented to have received an initial hearing screening by one month of age
- 90% or more of infants who do not pass their initial screen are documented to have an audiological evaluation by three months of age
- 85% of infants who have a diagnosed permanent hearing loss are enrolled in EI with documentation of enrollment by six months of age
- These events (95%), screening, audiological evaluation, diagnosis and intervention, are appropriately documented

The following goals and objectives were developed with input from a variety of stakeholders including the RIHAP advisory board and a Quality Improvement team (Attachments 9 and 10). Over a series of meetings, these groups evaluated the need within the state, determined how best to focus efforts to ensure that all infants receive timely hearing screening and follow up, and came to consensus about RI's approach over the next three years. To reduce loss to follow-up, RI will continue to utilize the nine strategies identified through the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative and will continue to develop and use a quality improvement plan guided by the Model for Improvement. RI will also engage in evaluation of all of the strategies and activities that are implemented through this work.

The NICHQ Learning Collaborative for Newborn Hearing Screening identified nine strategies that are effective in reducing the number of infants that are lost to follow-up. From 2007 to 2012, RI EHDI implemented many of these strategies. In RI, hospital staff use scripted messages to communicate with parents whose infants do not pass the initial screening test, screeners schedule follow-up appointments and ascertain the name of the infants' primary care providers, and EHDI staff use FAX-back forms with primary care providers, make reminder calls for follow-up appointments, and have made enhancements to the data tracking system. Additionally, electronic transfer of (EI data was developed to streamline the EI referral process. RI EHDI has assessed and will continue to assess the effectiveness of the current established

above mentioned strategies and will incorporate into the proposed project plan any change activities needed to ultimately enhance these strategies.

RI will use quality improvement strategies which are described in the activities below each goal and objective to reduce the loss to follow up after the failure to pass a newborn hearing screen. Several of the objectives have an associated quality improvement activity and plan/do/study act cycle (Attachment 11). The quality improvement activities were developed with a team of stakeholders, which includes individuals who have expertise in quality improvement. The team includes audiologists, HEALTH staff who have been trained specifically in Continuous Quality Improvement by North Carolina's Center for Public Health Quality, data specialists, a neonatologist and others.

As previously mentioned, RI EHDI has already formed a CQI team and plans to work on improving the loss to follow-up in the newborn hearing screening process. The team has developed an aim statement, to reduce the number of infants lost to follow-up after failure to pass a newborn hearing screen; this will be expanded as needed during the CQI process. Although the team has already developed several ideas to test, they have not yet developed a charter, a document that organizes all project information into one document. This is one of the next steps in the project. The team will also develop a balanced set of measures, which helps assure that the system(s) is improved. The measures, which will include outcome, process, and balancing measures, will be linked to measurable gains in the aim statement, will show improvement quickly, and will include outcomes. The team will do a pilot test or PDSA with new measures and will include operational definitions and a measure table for consistent data collection. As the team continues to investigate the current process of newborn hearing screening and follow-up, the team will identify additional areas for improvement and change. The team will use Model for Improvement and Lean Method CQI tools, including Gemba Walks, to identify where there might be waste in a process, and Value Stream Process Maps, to identify where the flow in a process stops or slows down. The team will look at the root cause of problems and will prioritize ideas using tools such as the fishbone diagrams and the 5 Whys template. The team will conduct the various tests of change cycles and will then spread and sustain any change ideas that are successful.

Engaging in quality improvement activities in different settings and at each of the stages in which follow up could break down will allow RI to determine whether there are key points at which children become lost to follow-up. The quality improvement and the plan/do/study/act cycles allow for processes and systems to be examined in sufficient detail so that weaknesses can be identified and small changes that would improve systems and processes can be implemented and evaluated. Although RI has already identified six different tests of change, which may help improve various processes, RI EHDI will continue to examine additional areas in which the newborn screening and follow-up processes and systems may be improved. For example, RI will continue to evaluate the processes and systems in place in both the hospitals' newborn nurseries and for home births. RI will also look at whether there are factors that can be identified at birth that would reduce the likelihood of a family being able to follow up and how these factors can be addressed. In addition, RI will examine whether there are problems with reporting data and how these processes can be made more efficient and effective. RI will also use the quality improvement strategies to determine how the nine Learning Collaborative strategies are supporting newborn screening and follow up.

Strategies and tools will be developed, if needed, to support partners in newborn hearing screening. HEALTH anticipates that through this process there will need to be tools developed at the birthing hospitals, for midwives who attend home births, for staff at referral agencies and for audiologists. There are several staff at HEALTH, within the team that houses the newborn hearing screening program, who have attended professional development or who have continuing education around quality improvement. These staff will be available to support training needs as they are identified in the community or with other state partners. Integrating CQI into ongoing training for hearing screeners will also be an important vehicle for creating a broader understanding of the QI process, how it works, and how it can help RI achieve its goals. Tools will also be developed to support community partners as they engage with HEALTH in implementing and evaluating quality improvement activities.

QI activities not only measure the quality of services but can support the improvement of integration and coordination of culturally and linguistically appropriate and family-centered services. This is important with a high percentage of lost to follow-up infants who are living with families whose primary language is Spanish. Reducing health disparities is a priority for HEALTH and RI EHDI; efforts at HEALTH are designed to reach a diverse population with specific efforts targeted towards reaching those families from different cultures, who are linguistically diverse, who live in socio-economically challenged areas and who come from different areas of the state. HEALTH has expertise in the department to ensure that efforts are inclusive of diverse populations. Materials are developed in different languages and they are graphically culturally diverse. HEALTH supports all of its partners to use the Culturally and Linguistically Appropriate Services (CLAS) Standards and has offered training in how to implement them. If barriers such as low socio-economic status or those related to language are not addressed, health disparities will continue to strongly contribute to adverse outcomes.

HEALTH also has a commitment to family engagement. Frequently, programs and services are developed without family input and adequate consideration for their needs. This can result in programs that do not fully or effectively meet the needs of children and their families, including newborns with hearing loss. Hearing screening, treatment, and follow-up programs, services, and supports must be tailored to reach infants in multiple geographic areas (e.g. rural, suburban, and urban areas), and address language, income, and other barriers (e.g. lack of transportation and family isolation, etc.) that can affect access to services. HEALTH will reach out to families to participate closely in the activities related to this work.

RI has two important data systems that will support the implementation and measurement of the quality improvement strategies. The RI-EHDI data system is comprised of two essential data systems, RITRACK and KIDSNET. RITRACK is specific to newborn hearing screening and, as such, receives and stores demographic information, screening results, and diagnostic information. RITRACK is also used for tracking, quality assurance and follow-up purposes.

KIDSNET is Rhode Island's confidential, computerized child health information system that includes demographic and comprehensive health information on all children born in RI. This web-based system provides access to public health information by authorized users such as primary care physicians and audiologists. KIDSNET includes birth records and immunizations, has information from the Newborn Bloodspot, WIC, Healthy Homes and Childhood Lead Poisoning Prevention (including lead screening information, lead abatement status, and child address history), Part C Early Intervention, Newborn Developmental Risk Assessment, Home

Visiting, and the Birth Defects Programs, and includes newborn hearing screening data from RITRACK.

RITRACK and KIDSNET exchange data daily. Audiology diagnostic information is entered in KIDSNET or submitted on paper by community audiologists. Health care providers (including audiologists), maternal & child health programs, and other child service providers have access to KIDSNET information. KIDSNET was developed to ensure the provision of timely and appropriate pediatric preventive health services and follow-up. Currently, HEALTH and the Rhode Island Department of Education are working to link child health data with education (preK-12 data).

KIDSNET information is used for quality assurance, reducing loss to follow-up, informing new program activities, continuous quality improvement, and evaluation. In addition, KIDSNET is used to measure and monitor important trends in child health and its influences, including child hearing status. KIDSNET measures: 1) span the developmental stages of childhood and are gathered from subgroups defined by ethnicity, income, geographic region, and special needs including children with special health care needs and those in foster care, 2) provide a surveillance and early detection capacity to anticipate the need for specific services and interventions, 3) improve understanding of the mechanisms of child development and determine how changes in behavior, new health practices, and new policy interventions affect child health, and 4) measure the performance of the personal health care system, community service systems, and the broader public health system and how they affect child health.

The state's advisory committee, the Rhode Island Hearing Assessment Advisory Committee, which was created per general law, Section 23-13-13, determined membership. The Committee consists of stakeholder representatives from HEALTH, the Department of Human Services (Early Intervention), the Commission for the Deaf and Hard of Hearing, the Rhode Island School for the Deaf, parents of a child with hearing loss, a teacher of the deaf, the Director of the Oral Program, and the Rhode Island Hearing Assessment Program (Attachment 9). The Committee convenes on a quarterly basis; at these meetings, data are presented and reviewed and the group identifies change strategies and priorities for improvement. Prospective committee members interested in participating in this stakeholder group are presented to the committee for a vote; if approved, an invitation is made to join the committee.

The Rhode Island Title V Director also oversees the Division of Community, Family Health and Equity (DCFHE). The Newborn Hearing Screening Program is part of DCFHE's Perinatal and Early Childhood Health Team. Blythe Berger, the Team Lead of PECH, meets regularly with the Title V program managers group to coordinate and integrate efforts between all maternal and child health programs.

The Home Visiting Program, which includes the expanded services under HRSA's Maternal and Child Health Home Visiting (MIECHV) Initiative, is also part of the PECH Team and works closely with newborn hearing screening. A referral system from newborn hearing screening to home visiting to assist with newborn hearing screening and follow-up is already in place with the First Connections Home Visiting Program; plans to expand that coordination with the other MIECHV home visiting programs are under development.

Newborn Hearing Screening coordinates with Early Head Start (EHS) programs. Currently both programs are exploring data sharing options between KIDSNET and EHS data systems including "Child Plus," the most commonly used system. Data sharing capacity with

EHS is expected to increase over time. An EHS/EHDI partnership and data sharing proposal was presented to Head Start Directors and Nurses and they have agreed to exchange data with KIDSNET to help coordinate screening efforts with RI-EHDI and to help facilitate newborn hearing screening follow-up.

RI EHDI plans for the quality improvement team to work together to establish, advance, and maintain effective strategies for continuous improvements the program. The development and implementation of change activities in the proposed project will be incorporated into existing systems and processes. Most of the proposed changes are relatively low cost and do not require significant reconfiguration of existing systems. The changes should be easily sustainable. One of the benefits of QI is that it can be integrated into existing work as an important component of systems. During the grant project period, existing EHDI staff already familiar with QI will train and work closely with extended project partners. Enhancements, new or changed protocols will be shared with all, so that permanent staff will know the protocols and be familiar with the process once the project period ends. Engaging audiologists, midwives, hospitals, and Border States to focus efforts to improve the loss to documentation/loss to follow-up by utilizing specific interventions and quality improvement methodology will lead to establishing routine protocols and sustained improvement in the numbers of infants who receive appropriate and timely follow-up. Beyond the grant cycle, state funding will continue to support this work. All policies and procedures developed during the project will be well documented so that future staff can follow implemented processes for follow-up purposes.

Work plan

In 2013 RI formed a team of stakeholders to support quality improvement work around reducing loss to follow-up and increasing quality related to newborn hearing screening (Attachment 10) The QI team for this project includes the Rhode Island EHDI Coordinator, the RIHAP Medical Director, the RIHAP Administrative Audiologist, the EHDI data manager, the RIHAP follow-up coordinator, a RIHAP parent consultant, the KIDSNET manager, and the Early Intervention technical assistant and other HEALTH staff. Data systems available to support quality improvement and evaluation during this project are KIDSNET and RITRACK, previously described. Quality improvement strategies, including PDSA cycles were developed specifically around objectives and are described in detail below. The QI team presented the plan for this proposal to the Advisory Board and it was accepted. The QI team will promote and maintain a culture of quality improvement throughout the project plan. Additional detail including timelines and responsible staff is in Attachment 1,

Goal 1: Increase the number of infants who receive an initial hearing screen by 1 month of age, and ensure that screening results are documented.

*Objective 1.1 Evaluate screening and documentation at birthing hospitals to ensure that 100% of infants are screened and have documentation of screening by 1 month of age.
(EHDI target: all infants screened by 1 month of age)*

Strategy: In 2012, there were 222 infants who did not have documentation of receiving an initial hearing screen by one month of age. Of these, 193 were screened after one month, and 62 died. For 10 infants there is no screening information; of these, 8 were home births and 2 were

hospital births. It is important to understand these two groups as there may be issues around timely screening or timely documentation. For 10 of the infants there appears to be no screening, but for 193 the screening was delayed. It is possible that there is no documentation on a screening for these infants either because they were transferred to a different hospital for medical reasons or because they were residents of a border state. RI will study the data to try to determine what may be the root causes behind the missing screens and develop tests of change as needed to understand why there is missing information for any infant born in a hospital in RI. If this is an issue around information transfer between states, it will be addressed through the activities related to the border state data sharing agreement, Objective 1.3. Of the ten infants not screened, eight were home births; this is addressed in the following objective.

Objective 1.2: Increase the OAE screening rates performed in home deliveries from 67% to 100% by March of 2015. (EHDI target: all infant screened by 1 month of age)

Strategy: Currently, the home birth population has significantly lower rates of newborn hearing screening. Out of the 24 home births in 2012, there was no documented hearing screen for 8 (33%) infants. Engaging midwives and developing strategies to increase screening rates that are specifically targeted to midwives who attend home births is important particularly since the rates of home births are increasing.

Study of previous tests of change intended to increase the number of home birth hearing screenings revealed that the home birth population was not receptive to outside interventions considered intrusive to their home environment. The 3 midwives who attend home births will be trained to educate the family about the importance of hearing screening and follow-up. The EHDI QI team and other stakeholders believe that another effective way to improve screening in this population is to provide access to OAE equipment to midwives who attend home births (Change activity #1). During this change activity, one midwife who attends home births will be trained to both use OAE equipment and to report her screening results to RIHAP. If the infant fails the hearing screening, the midwives will notify RIHAP and assist the family with making a re-screen appointment for follow-up services. If the test of change is successful, RITRACK should have documentation of a completed hearing screen for all infants birthed by the midwife and whose family agreed to a hearing screen in the home. If data demonstrate effectiveness of this change activity, RI-EHDI will train the 2 additional midwives, which will result in a practice that can be disseminated statewide to ensure infants born at home are screened.

Objective 1.3: Ensure 100% of newborn hearing screens are documented in KIDSNET (EHDI target: all infant screened by 1 month of age)

Strategy: It is important to capture all information about newborn hearing screens in KIDSNET; this allows for both individual follow-up of children who need it and for analysis of statewide aggregate data to assess a variety of health outcomes. Rhode Island shares borders with Massachusetts and Connecticut. The RI EHDI program is responsible for screening all infants born in RI regardless of state of residence. An established data sharing agreement with other New England states permits exchange of information for infants who are Rhode Island residents but born and tested in other states. However, the agreement does not allow an exchange of information for infants who are born in Rhode Island (regardless of state of residence) but transferred to an out-of-state hospital. In other words, if an infant is born in RI, lives in a border

state, and is not screened before leaving the birthing hospital, data on screening done outside of the state cannot be obtained with the current agreement. The current border agreement will be modified to collect data from EHDI programs in other states so that the RI EHDI program receives all screening information on infants born outside of the state. In addition, Rhode Island will also commit to participate and host regional quarterly conference calls to discuss quality improvement projects with border states.

Goal 2: Reduce loss to follow-up after a failed newborn hearing screen

Objective 2.1 Ensure that all infants who fail a newborn hearing screen receive appropriate evaluation by three months of age, reduce loss to follow up rates by 15% annually

(EHDI target: ensure diagnosis by 3 months of age)

Strategy #1: Collaboration with medical homes may be an important way to reach the 32 infants lost to follow-up for whom hearing status is concerning, and the additional 45 who were not diagnosed by the recommended 3 months. Children who have a medical home are more likely to receive comprehensive care including recommended hearing screenings, audiology diagnostic follow-up, and EI services. Change activity #2 involves the medical home. Through this test of change, the RI-EHDI program will assist a Parent Consultant (a parent trained to support families and co-located with primary care) with using a Primary Care Provider (PCP) report (Attachment 12) at one primary care office. The PCP report lists patients that are in need of follow up after a failed hearing screening. Infants continue to be listed on this report until documentation of follow up is received. Currently, the PCP report is mailed to practices to remind providers of the importance and urgency of the EHDI 1,3,6, goals. There is not guidance around the use of the PCP report, instead it is up to the primary care site. RI EHDI will develop a script and clear guidance on how and when to work/follow-up with the families. From July - September 2014, the Parent Consultant in one primary care office will use the script and the RIHAP audiologist's guidance and support to follow-up with families who need a hearing screening, diagnostic evaluation, and/or services. The Parent Consultant will document all outreach to families. To determine if the test was successful, the RIHAP Coordinator will examine the Quarter 3 PCP report for the same primary care practice and will compare it to the Quarter 2 PCP report to see if any families have moved off the list. If they move off the list, they have scheduled or received follow up. The RIHAP Follow-up Coordinator will also look at KIDSNET documentation and notes taken by the Parent Consultant; this will determine whether and which of the Parent Consultant's efforts were helpful in moving families through the hearing assessment process. If the initial tests of change cycles are successful, the QI team will determine whether to adopt this strategy statewide. Physicians will also be supported to take advantage of additional outreach support through community programs such as home visiting and child care, if this is appropriate and they are unable to reach families through a phone call from the office.

Strategy #2: RI will also take advantage of data and information systems to reduce the number of children lost to follow up. An electronic cross-check with birth data in KIDSNET is used to recall infants who are either discharged prior to or have failed a hearing screen. Based on this KIDSNET data, RITRACK generates mail reminders to families whose infants need follow up. However due to increasingly transient populations, these mail reminders may not be the most effective way to reach families. To better reach highly mobile families, RI EHDI will

develop an online demographic form that captures cell phone and email addresses. The RIHAP audiologist will train screeners on how to complete the online demographic form. RIHAP will use cell phone information to send text messages to families about scheduling follow-up appointments. Change activity # 3 will test whether families are more likely to schedule an appointment if they're reminded via a text message.

To evaluate this test of change, the RIHAP Follow-up Coordinator and Parent Consultant will monitor RITRACK data. They will be able to determine if families who were texted were more likely to schedule follow up appointments than those who only received a mailed letter. If texting families is determined an effective measure after several cycles of testing, the QI team will spread this change to more families in need of follow-up.

HEALTH recognizes the essential nature of ongoing training to improve quality in all settings. Because newborn hearing screening is a collaborative effort by design, partners will be supported as they work with HEALTH. Regular meetings with partners, multi-state and community agency efforts, and frequent communication with stakeholders supports the work to be conducted collaboratively. State agencies in RI have a long history of collaboration; existing relationships allow state partners to work closely to improve outcomes for children. Site visits to support quality improvement at the birthing hospitals will also support collaboration. Communication is also supported by the capacity to share information electronically with greater numbers of people, such as in list serves. RI EHDI will also utilize the communications team at HEALTH to develop and disseminate any messages that would be relevant on a larger scale, such as information for families, or at the state or national level.

Strategy # 3: The RI EHDI program will build on the success of the home visiting program collaboration to work with other early childhood programs. For change activity #4, the RI EHDI program will test the success of a formal collaboration with one WIC agency. Currently formal collaboration with WIC offices does not exist, even though some of the infants who are lost to follow-up are WIC clients. During this test of change (#4), the State EHDI Coordinator will use KIDSNET to identify families of infants who are either lost to follow-up and/or who have not received a diagnosis by 3 months and who also receive services at a specific WIC agency. The WIC Parent Consultant, housed at HEALTH, will search in RIWebs (the WIC Electronic database) for the infants' contact information and will give this to the State EHDI Coordinator. If the contact information is different from that in RIHAP or KIDSNET, the State EHDI Coordinator will use the new information to contact the families. If the child is in need of a rescreen, the Coordinator will offer to schedule this at the next WIC visit. If the child needs a diagnostic evaluation, the EHDI Coordinator can also schedule this. Finally, if the contact information is the same, the State EHDI Coordinator will coordinate with the WIC agency and ask agency members to assist with scheduling. All steps of this process will be documented.

To determine if the test was successful, the RIHAP Follow-up Coordinator will use KIDSNET to review the status of infants who needed follow-up during the specified time frame, to see if they either scheduled, or received follow-up. She will cross-check the documentation for those infants who scheduled or received follow up to see if they were part of this new outreach activity with WIC. If the test is successful, most of the infants who needed follow-up and were contacted by the RIHAP follow up coordinator or the WIC Agency, will either be scheduled or have received a follow-up appointment. Coordination with other WIC sites will be developed after a study of the test of change with the first WIC site demonstrates success.

Because RI is using the above strategies to focus on 2 populations of children, those lost to follow-up and those who have delayed follow-up, it will be important to understand if any of the strategies are more successful for one group or the other and target efforts accordingly. It may be that there are systems changes, such as using text reminders, that will work more effectively with the infants who are outside the recommended EHDI targets, but that for families considered lost to follow up completely, more targeted outreach such as home visits are needed. The strategies listed above will also be evaluated to determine if they affect enrollment in Early Intervention within the appropriate time frame (6 months).

Goal 3: Improve documentation after a failed Hearing Screening regarding audiological evaluation and engagement in services

Objective 3.1 Increase the number of completed initial hearing screens, re-screens and audiological evaluations documented in RI-EHDI data system to reach 100% by March 2015.

Strategy #1: To increase the number of diagnostic results being entered into KIDSNET by audiologists, the RI EHDI program will offer continuing education credits for attending webinars that explain the urgency of follow-up, importance of reporting and the potential negative impact on language development if diagnosis is not documented in a timely manner.

Strategy # 2: As previously mentioned, a child could be considered lost to follow-up if they received recommended audiology follow-up but the diagnostic information was not reported back to RITRACK. HEALTH has made significant progress towards data sharing with the Department of Human Services (DHS), where Medicaid is located. RI EHDI proposes to collaborate with the Department of Human Services (DHS) to increase information exchange for better documentation. DHS has developed a secure Data Warehouse with individual level data, including Medicaid claims and diagnostic codes. Linkage to Medicaid data may provide some missing information including dates of audiology visits and hearing loss diagnoses. To test whether this linkage might improve loss to diagnosis, the RI EHDI QI team will conduct a test of change (#5). For the test, during quarter 4, the EHDI Data Manager will provide a DHS representative with a list of infants from that quarter who are in the follow-up or in process categories. The DHS representative will look in the Data Warehouse to determine if audiologists have submitted claims for any of the infants on the list. If Medicaid has documentation that RIHAP does not have, the RI EHDI QI team will continue with a larger test of change and expand the effort.

Strategy #3: As an additional measure to encourage audiologists to enter diagnostic results into the database, RI EHDI proposes to supplement the current training by providing audiologists with “Articulate Storyline” e-learning software. For change activity #6, one practice of audiologists, from January - March 2015, will have access to Articulate Storyline e-learning. Content will include the benefits of reporting, the mandate to report, and how to report into KIDSNET. RI EHDI predicts that the audiologists will use the Articulate Storyline e-learning system for assistance with documentation, and that, in turn documentation will increase. During the quarter that the test practice is using the Articulate Storyline software, the EHDI Data Manager will track the number of times the audiologists access the e-learning software. At the beginning of the next quarter, the RIHAP Follow-up Coordinator will look to see if there is a corresponding increase between accessing the Articulate Storyline software and documentation.

If Articulate is determined to be an effective training module, training will be available to all audiologists with a signed KIDSNET agreement.

Objective 3.2: Improve documentation of engagement in services by 6 months of age for children who are diagnosed with hearing loss. (EHDI target engagement in services by 6 months)

Strategy # 1: As previously mentioned, children can be considered lost to follow-up if they are diagnosed with a hearing loss and engaged in services, but information about their services is not shared with KIDSNET, which is one of the data systems that can be used to track a child's engagement in services. HEALTH has a data sharing agreement with the RI Executive Office of Health and Human Services (EOHHS), where Early Intervention is located. This data sharing agreement allows for information transfer between the state Early Intervention program and KIDSNET. The state level Early Intervention has data about children enrolled in all of the state's EI programs. However, there are some known challenges with this data. There can be a delay in getting the information into KIDSNET from EOHHS; if a child is discharged from one program and enrolled in another EI program, it can appear that the child has ended services. HEALTH will work with EOHHS to determine if this data is reported in a sufficiently timely way to determine how many families may not be engaged in services by 6 months of age.

Goal 4: Increase the number of rescreens/audiological evaluation for children who passed the initial newborn hearing screen but have risk factors for later hearing loss.

Objective 4.1: Increase by 50% the number of children who had completed diagnostic evaluations by six months of age if they passed their initial hearing screen but had risk factors for hearing loss.

(EHDI target all children diagnosed by 6 months)

Strategy:#1: Ensure that parents of children who have risk factors for hearing loss are educated about the importance of monitoring infants' hearing and the negative outcomes associated with infant hearing loss. RI EHDI does not have a complete understanding of the factors that prevent parents from seeking recommended follow-up for those infants born with risk factors for hearing loss; a low percentage of them follow-up in accordance with the recommended schedule. RI EHDI will use the first six months of this grant to evaluate what kind of information, education, and materials parents of children at risk for hearing loss, but who initially pass the screening, receive. This data and information will be presented to the QI team who will be charged with developing QI strategies and associated PDSA cycles to make improvements to the numbers of infants getting appropriate evaluation. The PDSA cycles will be implemented and evaluated in August of 2014.

Strategy #2: Once parents leave the hospital there may be other barriers that arise that impact their ability to bring their infants to necessary appointments. RI EHDI will explore the potential to link with existing services in which these children may be enrolled to ensure that they receive appropriate follow up. Similar to the activities described above, RI will use RITRACK and KIDSNET to determine if these children are enrolled in any other early childhood services. If children at risk for later hearing loss are enrolled in other early childhood programs such as Head Start, other child care, home visiting, or other support services, RI EHDI will work with these services to support families to ensure their infants receive appropriate

services. This may include assisting in scheduling appointments, supporting families who need translation, and sending home visitors to appointments with families. The QI team will develop an initial test of change with one program to determine if the program can help improve the rates at which families get rescreened or schedule audiological evaluations. These activities will be implemented and evaluated beginning in August of 2014.

Resolution of Challenges

There are 3 hospitals that provide diagnostic Auditory Brainstem Response (ABR) testing for infants; these 3 hospitals are centrally located in the Providence area, which leaves the other parts of the state without these services for young infants. Although RI is a geographically small state, an hour drive or bus ride (each way) may be a barrier to accessing follow-up for some families. It is particularly important that RI focuses on this factor because 30% of the infants who were lost to follow-up were born at a hospital in the Southern end of the state.

Families with multiple socio-demographic risk factors have historically been challenging to reach. They may not have access to transportation and they often have multiple children, which can be challenging when bringing a child in for an audiology appointment. These families may not understand the importance of follow up for newborn hearing screening and may also face cultural and linguistic barriers. RI plans to work with a variety of early childhood programs to implement specific outreach and engagement strategies to support parents with multiple risk factors. Working with home visiting agencies, Early Head Start agencies, and WIC sites for outreach, in-home hearing screens, and screens during WIC visits may potentially resolve this barrier. Although more heavily concentrated in the Providence area, additional audiology services beyond the ABR are available for infants and toddlers from 6 months to 3 years throughout the state, making this a less significant barrier once children become older.

Research shows that it is essential for families to understand the importance of newborn hearing screening and follow-up. It is likely that some of the reasons families do not return for scheduled follow-up is due to language barriers. Most of the Early Childhood programs in the state have extensive language capacity determined primarily by the needs of the communities in which they operate programs. Collaborating with the staff from these programs will expand the current language capacity of screening and follow-up services. It will allow families to gain education and information in a language they use comfortably. This is important because from demographic characteristics it is clear that there are infants lost to follow-up who speak a language other than English.

Evaluation and Technical Support Capacity

Progress on program performance will be monitored by the Newborn Hearing Screening Program Manager, the Medical Director for RIHAP, and the RIHAP Audiologist. In addition, the QI Team will meet monthly to ensure activities are being implemented according to the project time line. At both the QI Team meetings and the RIHAP advisory meetings, team members will review both data related to program performance and time frames to determine if the activities are occurring on schedule. Regular meeting schedules and close collaboration with partners allows for the early identification of any issues that require resolution. Project updates and results will be presented to the RIHAP Advisory group as well as to leadership within HEALTH. Loss to follow-up rates will be evaluated quarterly to determine progress toward

reducing them. Data measuring progress towards reaching the EHDI targets of 1,3,6 months will also be reviewed quarterly.

The RI EHDI information system will provide data to support evaluation efforts. This information system has evolved from a stand-alone data system collecting relatively few data elements to a sophisticated EHDI data system (RITRACK) collecting an abundance of data to meet tracking, surveillance, follow-up and reporting needs. Selected data are integrated with other child health data in KIDSNET to connect with medical homes, Early Intervention (EI), audiologists and others. These linkages facilitate collection and appropriate sharing of EHDI data. KIDSNET can run reports as frequently as needed; the reports will be customized to meet the needs of the evaluation. KIDSNET is organizationally located in the Center for Health Data and Analysis (CHDA) at HEALTH. CHDA has extensive capacity to support data collection and analysis and will support the evaluation efforts in this proposal. Data will be collected and input by community partners, cleaned at HEALTH and evaluated by both the QI team and the advisory board. Data is managed by a KIDSNET data manager who dedicates 20% of his time to working on Newborn Screening and Newborn Hearing Screening. All community partners who are expected to input data have been given access to KIDSNET which they can access through a web portal.

The evaluation will use both quantitative and qualitative methods. The evaluation will attempt to determine whether loss to follow-up, and failure to meet EHDI targets, is reduced by each strategy implemented during the project period using PDSA methodology. In addition, the impact of individual strategies can be tracked on a smaller scale in a more qualitative manner. The QI Team will develop run charts for ongoing activities to continue to monitor the success of each strategy. Data around case reviews completed, training for audiologists, evaluations from midwives, and use of hearing screening algorithms will be reviewed to ensure that these activities are occurring and that quality is maintained. Information from case reviews will be used on an ongoing basis to determine at which points infants may become lost to follow-up, and to continue to monitor whether there are specific characteristics of infants lost to follow-up that impact families' ability to seek services.

Information will be available about the number of infants who were screened by home birth midwives. This information will be analyzed to determine if the partnership with home birth midwives is having an impact. Information from primary care providers will also be collected and reviewed by the QI Team with provider practice staff to determine if children in selected primary care practice are receiving recommended follow-up.

Bi-annually, RITRACK will develop a list of individual infants lost to follow-up for the prior six months. This data will be matched with KIDSNET data to compare the success of engaging audiologists that underreport and those who do not report in a timely manner. The EHDI Data manager will monitor monthly data exchange of results obtained from bordering states. In addition, a process measure will be used to measure progress in establish regular data linkage with the DHS data warehouse and KIDSNET. In addition, KIDSNET data can assess how many infants from families receiving text reminders or an email were lost to follow-up before and after implementing strategies targeted to help this group.

QI staff will work with KIDSNET and the Early Childhood programs to determine which outreach and engagement strategies with early childhood programs are activities in successful.

Staff will evaluate which early childhood program linkages were most successful, and with which target populations, so that future efforts can be tailored to meet specific family needs.

After the initial year of implementation, demographic and other data about RI's target population will be evaluated to further inform strategy development and assess impact of strategies. KIDSNET captures language and ethnicity, which may allow RI to determine whether specific cultural groups experience greater loss to follow up, and have more challenges getting their infants services in the recommended time frames. To truly understand how different cultures experience newborn hearing screening and follow-up, focus groups may be necessary and can be implemented in year two of the grant. By using both qualitative and quantitative measures the RI-EHDI program will be able to determine if activities implemented through this grant were successful in reducing the lost to follow-up rate, getting infants into services at the earliest possible opportunity and meeting the needs of infants and families.

The leadership and advisory entities involved with this project have extensive experience with grant related work for the Newborn Hearing Screening Program, as well as similar programs. The PECH Team Lead will support the evaluation work and has over 15 years experience in data analysis and evaluation. The RIHAP medical director will also closely support evaluation efforts and has extensive experience in primary research and related evaluation. CHDA will also support the work when appropriate. Leadership at HEALTH and in CFHE have not published materials specific to newborn hearing screening, other than materials for families and providers. However, Dr. Betty Vohr, the medical director at RIHAP, has extensive publication experience.

Organizational Information

As the single public health agency in Rhode Island, the primary mission of the Rhode Island Department of Health is to prevent disease and to protect and promote the health and safety of approximately 1.1 million Rhode Islanders. The Department of Health has a staff of approximately 470 employees, and responsibility for all public health activities within the state, as there are no local or county health departments. Newborn hearing screening is a mandated program in Rhode Island per the Rhode Island General Laws, Section 23-13-13, and screening has been performed at all birthing hospitals since 1994. The Department of Health is responsible for assuring the implementation of the legislation and has the authority to run the program. Newborn Hearing screening is located in the PECH team in the Division of Community, Family Health and Equity (Attachment 5). Other programs within HEALTH include Infectious Disease, Licensing, Facilities Regulation, Center for Communication and the Center for Health Data and Analysis. Programs within the PECH team include, Newborn Metabolic and Developmental Screening, Home Visiting, WIC, Race to the Top Early Learning Challenge, and Child Care Health Consultation. The location of the Newborn Hearing Screening work within the PECH team ensures that it can be closely linked to many other early childhood programs that support healthy development and positive outcomes.

To meet the goals and objectives of this project, the QI Team will oversee the implementation of the activities. This team is comprised of key partners from organizations and state agencies (Attachment 10). HEALTH will provide support to the QI team, HEALTH is a strong supporter of QI and is currently in the process of increasing quality improvement efforts for accreditation through the Public Health Accreditation Board (PHAB). The plan/do/study/act

(PDSA) cycle is a four-step model currently being used to carry out change within HEALTH. A culture of Quality Improvement (QI) throughout a health department is necessary to achieve and then maintain Public Health Accreditation. Several key personnel within HEALTH have been recently trained in QI through the Public Health Foundation. Quality Improvement training was also provided to personnel in the Division of Community, Family Health and Equity through the Center for Public Health Quality in North Carolina. The Center for Public Health Quality's (CPHQ) mission is to collaborate with local, state, and national partners to transform the public health system to foster and support continuous quality improvement. Key personnel within HEALTH will be available to provide guidance and advice to the EHDI Quality Improvement team to meet the goals and objectives proposed in this application. Monthly meetings of the Quality Improvement Team will occur throughout the project period to ensure coordination of efforts among participating agencies, solicit parent/family input, and provide updates on progress. Updates will also be provided to all stakeholders in the RI EHDI system (EHDI partners) at RIHAP Advisory Committee meetings.

With 20 years of experience screening all newborns for hearing loss, HEALTH and its partners, including Women and Infants Hospital (RIHAP), are well positioned to carry out the activities and reach the objectives described in this application (job descriptions and biographical sketches for key personnel are provided in Attachments 2 and 3 respectively). Descriptions are not included for staff contributing less than 25% of their time job. The organizational base for this project within the Rhode Island Department of Health is in the Division of Community, Family Health and Equity. The Division Director is Ana Novais, who also serves as the Title V Director for the State. Within this Division, the Newborn Hearing Screening Program is part of the Perinatal and Early Childhood Health team. The Lead of this team is Blythe Berger, ScD, who is responsible for all early childhood programs. Also within this office is leadership for the Newborn Developmental Risk Assessment Program and First Connections Program (home visiting), both of which work closely with the Newborn Hearing Screening Program. In addition, the division leaders and other team leads will provide leadership and guidance for the project. Letters of support have been provided from the Division and Title V, and Chief of the WIC program (Attachment 13). Several key personnel within HEALTH have been recently trained in QI through the Center for Public Health Quality in North Carolina and will be available to provide guidance and advice to the EHDI Quality Improvement team to meet the goals and objectives proposed in this application. In addition, key members of the QI team attended the NICHQ collaborative offered to RI in 2011.

The project director, Liza Then, is the Newborn Hearing Screening Manager and the EHDI coordinator for the RI Department of Health. Ms. Then will provide oversight for the project and coordinate with other relevant statewide efforts. The EHDI Coordinator is a liaison between the CDC EHDI cooperative agreement data project, the state EHDI program, and the HRSA Universal Newborn Screening grant. Ms. Then attended the NICHQ learning Collaborative in 2011.

The KIDSNET Manager, Ellen Amore, has worked with the hearing screening program for twelve years and will continue to participate on the QI Team. Ms. Amore also oversees the CDC EHDI grant. KIDSNET is part of the Center for Health Data and Analysis (CHDA). CHDA includes epidemiologists as well as data and evaluation experts who are available to assist with evaluation. Ms. Amore will be responsible for facilitating the planning and

exploration of the Medicaid data exchange with DHS. The EHDI data manager will monitor and track all EHDI electronic file imports into KIDSNET, resolve errors for all electronic records that did not successfully transfer automatically into KIDSNET, generate and monitor routine and ad hoc data reports from KIDSNET, and execute KIDSNET EHDI data quality assurance activities. She will be responsible for modification and new reports from KIDSNET and RITRACK.

The Center for Public Health Communications provides support to programs in the division, including translation, brochure/materials development, publications and other services. Because these programs are all within the same department and have established partnerships, mutual leadership and close professional relationships foster collaboration. This Center also has extensive experience developing and disseminating information and materials that are culturally and linguistically appropriate.

The Rhode Island Department of Health Newborn Hearing Screening Program contracts with the Rhode Island Hearing Assessment Program (RIHAP) at Women and Infants' Hospital to provide administration of universal newborn hearing screening at each of the 7 birthing hospitals in the state. RIHAP also facilitates early diagnostic identification of permanent hearing loss, ensures smooth transitions to Early Intervention and education services, and collaborates with parents and professionals. RIHAP will provide clinical and program staff for activities in this grant to ensure coordination with Early Childhood programs, audiologists, and birthing hospitals. RIHAP has a dedicated follow-up coordinator that ensures clinical and programmatic activities, coordinates with community partners, and assists with data oversight. RIHAP has dedicated hearing screeners available to conduct screenings in community settings, as well as expand audiology capacity if necessary.

There are three staff at RIHAP who will support this project. Dr. Betty Vohr, MD, is a professor of Pediatrics at Brown University School of Medicine. Dr. Vohr has over forty years of experience in the field of neonatology and has been the Medical Director of the Rhode Island Hearing Assessment Program since 1990. Dr. Vohr was the chair of the Joint Commission on Infant Hearing from 2005 to 2007. She will serve on the management team for this grant and will contribute to the evaluation and any research or presentation efforts related to this grant. Tunisia Johnson, AuD, CCC-A, oversees the clinical implementation of RIHAP programs and technical staff at the screening sites throughout Rhode Island. She facilitates educational seminars, prepares and monitors clinical statistics, and interfaces with statewide agencies. Elsbeth Brown, the Parent Consultant, brings eight years of personal experience as a mother of a child with hearing loss. Elsbeth can support families in navigating the often confusing world of communication choices and education for the deaf and hard of hearing. She also conducts monthly support groups with families that have children who are deaf and hard of hearing. RIHAP has long been committed to providing services that are culturally and linguistically competent; it has translation capacity if needed and a culturally diverse staff who have all received CLAS training.

Two committees available for oversight of the project include the RIHAP Advisory Committee, which is mandated by law, and the Deaf and Hard of Hearing Advisory Committee (D/HH), which addresses practical issues facing parents of and professionals working with children who have hearing loss. This D/HH committee is a partnership of the Rhode Island Early Intervention Program (EI), HEALTH, and the Commission on Individuals who are Deaf

and Hard of Hearing. There is a long history of collaboration between EI and the hearing screening program and EI is well represented on the RIHAP Advisory and D/HH Advisory Committees. Brenda Duhamel, Chief of Family Health Systems and Part C Coordinator, attends these meetings on a regular basis and is available for collaboration on this work. Early Intervention partners at the Sherlock Center on Disabilities for training and technical assistance and Resource Specialists have been identified as part of this collaboration. Additional support for the grant activities will be provided by community and other partners; letters of support are provided in Attachment 13.

The project Organizational Chart (Attachment 5) provides a structural overview of the agencies and organizations who will contribute to this project. The Program Manager will promote collaboration among all project participants and strive to ensure that the system changes and strategies identified to reduce loss to follow-up are sustainable in the future and that the positive impacts of the project benefit the program on an ongoing basis. Whenever possible and appropriate, efforts will be made to disseminate and share project findings with EHDI partners in other states.

HEALTH has a longstanding commitment to ongoing assessment and understanding of the needs of the populations it serves. HEALTH uses data from annual Maternal and Child Health Needs Assessments and targeted geographic community health assessments, HEALTH is able to understand how the health and other needs of families change over time and is able to make program and systems changes accordingly. HEALTH also uses statewide data from state agency partners to understand if state data supports community feedback. This has been instrumental in identifying needs that communities may not note, or confirming where to target efforts. HEALTH will support the work of this proposal through its ongoing needs assessments. This will also allow HEALTH to confirm whether efforts developed and implemented in this grant improve outcomes.

RI is excited about this opportunity to expand its current efforts to reduce loss to follow-up. All participants clearly understand the benefits of addressing hearing loss at the earliest possible point on both an individual and population based level. RI has long focused efforts on offering children the opportunity to reach their full potential. This initiative seeks to further integrate and enhance systems of services for young children and their families and moves Rhode Island farther toward that important goal.