

GOALS AND OBJECTIVES	ACTIVITIES/STEPS	DATA/EVALUATION	TIMEFRAME FOR ASSESSING PROGRESS	PROGRAM STAFF RESPONSIBLE	GREEN = Completed on time YELLOW = Cautionary (may not meet time frame) RED = Did not meet time frame
<b>Goal 1:</b> Select and recruit a team of stakeholders for quality improvement measures for years 1 through 3 by July 1, 2014.					
<b>Objective 1.1:</b> Identify and Recruit stakeholders to participate in a collaborative with the VTEHDI program for reducing loss to follow up by May 1, 2014	<b>Activity 1.1.1:</b> Identify potential team members to include a pediatric audiologist, a parent, EHD IProgram Director , data manager and Early Intervention Coordinator.	<b>Measure 1.1.A:</b> Collaborative roster <b>Data Source:</b> Meeting minutes.	Start:April 2014 End:May 2014	Program Director	
<b>Objective 1.2:</b> Initiate first meeting of the collaborative group by June 30, 2014 and develop formal meeting shedule by August 1, 2014	<b>Activity 1.2.1:</b> Initiate first meeting of the collaborative group by June 30, 2014  <b>Activity 1.2.2:</b> Formal meeting schedule to be developed by August 1, 2014	<b>Measure 1.2.A:</b> Initiate first meeting of the collaborative group by June 30, 2014  <b>Measure 1.2.B:</b> Documentation of Attendance <b>Data source:</b> meeting minutes	Start: April 2014 End: March:2017	Administrative Assistant and Program Director	
<b>Objective 1.3:</b> Creating an Effective Team: coach mentor and build a highly performing collaborative team.	<b>Activity1.3.A</b> Document stages of development- Forming, Storming, Norming and Performing.	<b>Measure 1.3.A:</b> Member checklists at each stage of development will be administered by the Team Lead. <b>Data source:</b> Baseline: 0% Target: 80% <b>Evaluation of Activities:</b> Member Checklist at each stage of team development and a satisfaction survey to individual team members administered annually.	Start:April 2014 End:March 2017	Program Director, Administrative Assistant, Data Manager, Parent, Pediatric Audiologist Early Intervention Coordinator, Chapter Champion and culturally diverse representative.	
<b>Goal 2:</b> Develop an overriding AIM statement for quality improvementmeasures in reducing loss to follow up in Vermont by August 1, 2014					

<p><b>Objective 2.1:</b> By August 1, 2014 the VT collaborative team for loss to follow up will develop an overriding AIM statement for the state of Vermont</p>	<p><b>Activity 2.1.1:</b> The team will develop an overriding AIM statement for Vermont</p>	<p><b>Measure 2.1.A</b> Minutes of team/stakeholder meetings including AIM Statement.</p>	<p>Start: April 2014 August 1, 2014</p>	<p>Program Director, Administrative Assistant, Data Manager, Parent, Pediatric Audiologist and Early Intervention Coordinator.</p>	
<p><b>Goal 3:</b> Reduce loss to follow up for Vermont infants by 5% per year for grant years 1, 2 and 3 through the implementation of Plan, Do Study Act (PDSA) Cycles. Baseline data from 2011, 2012 and 2013 loss to follow up rates in Vermont will be compared with 2014 through 2016..</p>					
<p><b>Objective 3.1:</b> Implement a plan for outpatient hearing rescreening/screening appointments to be made prior to discharge at all 12 Vermont birth hospitals beginning in year 1 and continuing through year 3.</p>	<p><b>Activity 3.1.1:</b> PDSA cycles to be initiated for scheduling outpatient appointments prior to discharge at our largest tertiary care hospital, Fletcher Allen Health Care by August 1, 2014.</p> <p><b>Activity 3.1.2:</b> PDSA cycles to be initiated for scheduling outpatient appointments prior to discharge at all other birth hospitals in Vermont beginning in year 2</p>	<p><b>Measure 3.1.A:</b> Review all infants at FAHC needing follow up screening through FAHC electronic health record known as PRISM. Compare loss to-follow up rates with annually with baseline data from 2011, 2012 and 2013. <b>Data source:</b> CHHS database and PRISM  <b>Evaluation:</b> Satisfaction survey sent to families of infants scheduled for outpatient hearing screenings prior to discharge annually. Reduce loss to follow up rates by 5% per year as compared to baseline data from 2011, 2012 and 2013.</p>	<p>Start: April 2014 End: March:2017</p> <p>Start: April 2015 March:2016</p>	<p>VT Collaborative Team</p> <p>VT Collaborative Team</p>	
	<p><b>Activity 3.1.3:</b> Quarterly Hospital Report Cards identifying loss to follow up will be distributed to all 12 birth hospitals in Vermont</p>		<p>Start April 2014 End: March 2017</p>	<p>Data Manager</p>	

<p><b>Objective 3.2:</b> VTEHDI program to care manage all infants needing re-screening appointments through communication with birth hospital, PCP, family, WIC providers, Home Visit Program providers and Community Health Team providers during years 1 through 3 of the grant..</p>	<p><b>Activity 3.2.1:</b> Review policy and procedures</p>	<p><b>Measure:</b> We will use the CHHS database for any changes to policy/procedure and make decisions based on changes in the data. Baseline data for comparison will be from 2011, 2012 and 2013. <b>Data Source:</b> CHHS Database</p>	<p>Start June 2014 End : March 2017</p>	<p>Program Director, Project Coordinator, Staff Audiologist</p>	
	<p><b>Activity 3.2.2:</b> Identify small tests of change for policy/procedure improvements</p>		<p>Start June 2014 End : March 2017</p>	<p>Program Director, Project Coordinator, Staff Audiologist</p>	
	<p><b>Activity 3.2.3:</b> Test changes, evaluate and expand where appropriate.</p>	<p><b>Evaluation:</b> 1. Compare our data to JCIH national standards for 1, 3, 6 quarterly. 2. Interview stakeholders affected by policy/procedure changes for feedback annually.</p>	<p>Start June 2014 End : March 2017</p>	<p>Program Director, Project Coordinator, Staff Audiologist</p>	
<p><b>Objective 3.3:</b> Foster continued collaboration with pilot sites including primary care and homebirth midwives: years 1 through 3.</p>	<p><b>Activity 3.2.1:</b> Mentor ,educate and support pilot sites with primary care providers and midwives. Develop and test PDSA cycles for small tests of change.</p>	<p><b>Measure:</b> PDSA cycles will be used to measure success through data driven outcomes for comparison. <b>Data Source:</b> CHHS database <b>Evaluation:</b> Reduce loss to follow-up by 5% overall in pilot sites. Baseline data will be collected from 2011, 2012 and 2013.</p>	<p>Start: April 2014 End: March 2017</p>	<p>Program Director, Project Coordinator, Staff Audiologist in collaboration with the Vermont Collaborative Team</p>	
	<p><b>Activity 3.3.2:</b> Quarterly Reports for identifying infants needing re-screening.</p>	<p><b>Measure:</b></p>	<p>Start: April 2014 End: March 2017</p>	<p>Data Manager/Project Coordinator</p>	
	<p><b>Activity 3.3.3:</b> Train providers to report electronically to the CHHS database using the web based application</p>	<p><b>Measure:</b> Documentation of training log. <b>Data Source:</b> Excel file <b>Evaluation:</b> Training satisfaction survey</p>	<p>Start: April 2014 End: March 2015</p>	<p>Data Manager</p>	
	<p><b>Activity 3.3.4:</b> Provide quarterly newsletter "Tips &amp; Hints."</p>	<p><b>Measure:</b> documentation folder of quarterly reports</p>	<p>Start: April 2014 End: March 2017</p>	<p>Project Coordinator</p>	
<p><b>Objective 3.4:</b> Collaborate with pediatric audiologists serving Vermont's infants for timely and complete diagnostic evaluations: years 1 through 3.</p>	<p><b>Activity 3.4.1:</b> Introduce NICHQ monthly audiologist checklist form to pediatric centers. PDSA Cycles will be initiated for the introduction.</p>	<p><b>Measure:</b> Documentation of PDSA cycles and documentation of completed checklist. <b>Data Source:</b> CHHS database and excel file <b>Evaluation:</b> 1. Satisfaction survey with audiologists regarding use of checklist at the end of year 1. 2. Monitor loss to diagnostic data quarterly and compare to baseline data for 2011, 2012 and 2013.</p>	<p>Start: April 2014 End: March 2017</p>	<p>Staff Audiologist</p>	

	<b>Activity 3.4.2:</b> Implement electronic reporting by pediatric centers directly into the CHHS database.	<b>Measure:</b> Documentation of training log. <b>Data Source:</b> Excel file <b>Evaluation:</b> Training satisfaction survey	Start: April 2014 End: March 2015	Data Manager	
<b>Objective 3.5:</b> Expand relationships with WIC, Home Visiting program and Community health Teams by the end of year 2	<b>Activity 3.5.1:</b> Learn about Wic, Home Visiting Program and Community health Teams	<b>Measure:</b> Identify ways in which VTEHDI can collaborate with these programs in reducing loss to follow-up for re-screening.	Start: April 2014 End: March 2015	Program Director and Project Coordinator	
	<b>Activity 3.5.2:</b> Develop PDSA cycles for collaborating with these programs for the loss to follow-up cohort	<b>Measure:</b> Identify loss to follow-up infants in the programs. <b>Data Source:</b> CHHS database	Start: April 2014 End: March 2015	Program Director and Project Coordinator in collaboration with the Vermont Collaborative Team.	
	<b>Activity 3.5.3:</b> Identify and implement a plan for providing screening services to infants in the loss to follow-up cohort.	<b>Measure:</b> Compare pre and post screening implementation plan with programs. <b>Data Source:</b> CHHS database <b>Evaluate:</b> Family and stakeholder satisfaction survey	Start: April 2014 End: March 2016	Project Coordinator	
<b>Objective 3.6:</b> Attend quarterly meetings with New England border states to reduce loss to follow-up of infants born in one state and screened in another state: years 1 through 3.	<b>Activity 3.6.1:</b> Participate in conference calls.	<b>Measure:</b> Meeting and Attendance minutes. <b>Data Source:</b> Meeting folder and CHHS database. <b>Evaluation:</b> Survey for New England EHDI coordinators by the end of year 3.	Start: April 2014 End: March 2017	Program Director	
<b>Goal 4:</b> Strengthen and expand collaborative relationships with early childhood programs including Head Start and Part C.					
<b>Objective 4.1:</b> Support hearing screening, training, education and mentoring in Early Head Start and Part C programs: years 1 through 3.	<b>Activity 4.1.1:</b> Education, mentor and training support to Early Head Start programs	<b>Measure:</b> Contact and training log. <b>Data Source:</b> Excel file <b>Evaluation:</b> Satisfaction survey by the end of year 1	Start: April 2014 End: March 2017	Project Coordinator	
	<b>Activity 4.1.2</b> Educate and train for electronic reporting of hearing screening data through CHHS database.	<b>Measure:</b> Documentation of training log. <b>Data Source:</b> Excel file <b>Evaluation:</b> Training satisfaction survey by the end of year 1.	Start: April 2014 End: March 2015	Data Manager	
<b>Objective 4.2:</b> Continue funding and relationship with the Vermont Parent Infant Program (VTPIP): years 1 through 3.	<b>Activity 4.2.1:</b> Implement PDSA cycles of quality improvement with EI provider or parent attending diagnostic audiology visits with families.	<b>Measure:</b> log of visits attended. <b>Data Source:</b> excel file <b>Evaluation:</b> Satisfaction survey annually with families.	Start: April 2014 End: March 2017	VTPIP Coordinator in collaboration with the Vermont Collaborative Team.	

		<p><b>Measure:</b> Documentation of PDSA cycles and documentation of completed checklist.</p> <p><b>Data Source:</b> CHHS database and excel file</p> <p><b>Evaluation:</b> 1. Satisfaction survey with EI providers regarding use of checklist at the end of year 1. 2. Report loss to EI quarterly and compare data to baseline for 2011, 2012 and 2013.</p>	<p>Start: April 2014 End: March 2017</p>	<p>VTIPI Coordinator in collaboration with the Vermont Collaborative Team.</p>	
	<p><b>Activity 4.2.2:</b> Implement use of NICHQ early intervention checklist. Use PDSA cycles for introduction.</p>	<p><b>Measure:</b> Meeting minutes</p> <p><b>Data Source:</b> Excel file and CHHS</p> <p><b>Evaluation:</b> Compare Vermont data to JCIH national standards for EI by 6 months quarterly.</p>	<p>Start: April 2014 End: March 2017</p>	<p>VTIPI Coordinator in collaboration with the Vermont Collaborative Team.</p>	
	<p><b>Activity 4.2.3:</b> VTIPI Coordinator to participate in the Vermont Collaborative Team</p>				
<p><b>Goal 5:</b> VTEHDI will identify and implement a plan for financial sustainability for the program by the end of year 3..</p>					
	<p><b>Activity 5.1.1</b> Identify key stakeholders</p>	<p><b>Measure:</b> List and commitment of key stakeholders</p> <p><b>Data Source:</b> Excel file</p>	<p>Start: April 2014 End: March 2015</p>	<p>Program Director, Newborn Screening Chief, MCH Leadership</p>	
	<p><b>Activity 5.1.2</b> Develop long term VTEHDI budget.</p>	<p><b>Measure:</b> Develop budget</p> <p><b>Data Source:</b> Excel file</p>	<p>Start: April 2014 End: March 2015</p>	<p>Program Director, Newborn Screening Chief, MCH Leadership</p>	
	<p><b>Activity 5.1.3</b> Set up meeting schedule and develop sustainability plan.</p>	<p><b>Evaluation:</b> Approved implementation plan and budget by CSHN.</p>	<p>Start: April 2016 End: March 2017</p>	<p>Program Director, Newborn Screening Chief, CSHN Leadership</p>	

### **Section 1: Project Identifier Information**

Grant Number: HRSA-14-006

Project Title: Reducing Loss to Follow-Up after Failure to Pass Newborn Hearing Screening

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#### *i. Abstract*

The goal of this competitive renewal from HRSA is to reduce loss to follow-up by 5% per year over the 3-year grant agreement using the quality improvement methodology, Plan-Do-Study-Act (PDSA) approach. In 2011 the Vermont Early Hearing Detection and Intervention Program (VTEHDI) loss to follow-up rate of was 39%.

As part of the grant proposal VTEHDI will identify, recruit and build a highly effective collaborative team of stakeholders to include VTEHDI staff, pediatric audiologists, early intervention providers, our chapter champion, parents and a member of our culturally diverse community to lead quality improvement for universal newborn hearing screening. The Vermont Collaborative Team and the Vermont Department of Health Hearing Advisory Council will guide the development of PDSA cycles for quality improvement measures. These cycles will include scheduling outpatient re-screening appointments prior to discharge, care management of all infants needing follow up screening or diagnostic appointments, continued collaboration with our Primary Care Provider pilot sites and Part C programs, expanding collaboration with WIC, the home visiting (VT Family Nurse Partnership) program and VT Blueprint for Health community health teams at Fletcher Allen Health Care, and quarterly conference calls with our border states who provide hearing services to Vermont's infants.

We will evaluate our progress in quality improvement using both qualitative and quantitative analysis. The Childhood Hearing Health System database, part of the fully integrated SPHINX database at the Vermont Department of Health, will be used to collect, track and report data necessary for quality improvement. The VTEHDI program will compare Vermont's statistics to the JCIH national standards: screen by 1 month, diagnose by 3 months and early intervention by 6 months of age. Additionally we will use the database to monitor loss to follow-up quarterly, and will report data to our external stakeholders through the use of reports and hospital report cards. Additionally we will use qualitative analysis, interviews and satisfaction surveys, to measure and improve the quality of the VTEHDI program. Finally, the goal of the VTEHDI program is to reduce loss to follow-up annually by 5%. We will be using baseline data from 2011, 2012 and 2013.

#### *ii. Program Narrative*

### INTRODUCTION

The Vermont Early Hearing Detection and Intervention Program (VTEHDI) proposes to use this HRSA grant to decrease our loss to follow-up rate by 5% per year as compared to our baseline data from 2011, 2012 and 2013. Quality improvements will be based on small tests of change learned at the NICHQ Collaborative, using the Plan-Do-Study-Act approach to improvement. Thus we will focus on the model of improvement developed by *Associates in Process Improvements*. The model encourages us to ask the following three questions in conjunction with the PDSA cycles:

What are we trying to accomplish?

How will we know if a change is an improvement?

What changes can we make that will result in improvement?

The first task of the VTEHDI program will be to assemble a collaborative working team to include VTEHDI staff, a pediatric audiologist, a parent, at least one early intervention provider, our AAP chapter champion and a member from a culturally diverse community.

We will accomplish reducing loss to follow-up by continuing to collaborate with birth hospitals, Early Head Start providers, Part C providers, Homebirth Midwives, audiologists and primary care providers (PCP). We currently have 11 PCPs and 20 licensed midwives participating as pilot sites and providing Otoacoustic Emission (OAE) hearing screening. The PCP pilot project began in 2010 and the midwife pilot project in 2011. All four Early Head Start Programs are also now collaborating with VTEHDI and sharing data. In addition to the previously listed stakeholders, we intend to initiate collaborative relationships with the WIC program, the Home Visiting Program and the Community Health Teams at our largest tertiary care hospital, Fletcher Allen Health Care. The Community Health Teams are part of Vermont's Blueprint Project, promoting the Medical Home to improve the health of Vermonters. Our proposed project will expand the scope of our current program activities, moving us closer to the Joint Commission's recommendation of screen by 1 month, diagnose by 3 months and intervention by 6 months. Finally, we have a dedicated follow-up coordinator for care managing infants in need of a hearing screen or rescreening, as well as a dedicated audiologist for managing infants referred for diagnostics. Moreover, we believe the synergy of these efforts will reduce lost to follow-up in Vermont.

Vermont will complete its 11th full fiscal year of universal newborn hearing screening and follow-up at the end of December. Although not mandated by state law, the vast majority of families choose to have their babies screened. The majority of our births are screened prior to hospital discharge or on an outpatient basis at a community hospital or audiology practice. Infants born at home are screened by their licensed midwives. Even though Vermont screening statistics are comparable to states across the country where screenings are mandated, there are still a number of babies who do not receive a final screening or diagnostic result, or whose results are not getting reported back to the Vermont Early Hearing Detection and Intervention Program (VTEHDI), that are lost-to-documentation.

Currently, we reach out by phone and mail to the families and primary care provider of every baby born in Vermont who did not pass or who was discharged from the hospital without a screening. VTEHDI's two full time audiologists and one part time audiologist that are responsible for helping to coordinate outpatient-screening services as

close to home as possible. The importance of newborn hearing screening and follow-up is discussed in our communications with families and primary care providers.

We also reach out by mail to the small number of families who declined the hospital screen. Written information is provided regarding why we universally screen, where their baby can receive hearing screening, and our contact information. For families of babies who pass their hearing screening, but who have one or more high risk factors for late onset hearing loss, we send a letter informing them of the recommended intervals for periodic hearing screening and where they can receive screening.

The birth hospitals are responsible for sharing results at discharge with the family and PCP. Because of the very high rate of health care insurance, and the presence of several FQHC providers, all babies born in Vermont have access to a primary care provider. Not all families choose to have their babies seen in a traditional primary care, medical home setting. Some families choose to receive their care and the care of their children through the services provided by a homebirth midwife or non-traditional medical provider.

Our VTEHDI staff connects directly with the PCP (traditional or non-traditional) to discuss follow-up and help with care coordination. Though we feel this outreach is successful, there is room for improvement in reducing the number of babies in Vermont who are either not being screened initially or are not receiving a follow-up screening.

To document screening and outcomes, VTEHDI has successfully developed and instituted enhancements to the Childhood Hearing Health System Database (CHHS) that went live on September 26, 2013. CHHS is part of the fully integrated database at the Vermont Department of Health that includes electronic birth records, electronic death records, newborn screening, newborn hearing screening, and the immunization registry. Since the database for hearing screening was developed in 2009 stakeholders have been able to have read-only access to the data system. The new enhancements funded by the CDC cooperative agreement include electronic reporting of outpatient hearing screening for pilot sites, hospitals, PCP providers, Early Head Start providers and licensed midwives. Additionally, audiologists statewide can electronically report diagnostic results. A new tab was developed in the database for capturing hearing screening results for all children with high risk factors for developing hearing loss, through age 5. The CHHS database has been integral in improving our tracking, reporting and surveillance capabilities. The state is also pursuing expanding the database to document developmental screening of all children.

In the summer of 2012 VTEHDI began its participation in the HRSA sponsored Learning Collaborative for quality improvement. In addition to the Learning Collaborative, VTEHDI was invited by the Vermont Agency of Human Services to participate in the Agency Improvement Model (AIM) Project. Both projects approached quality improvement through small tests of change using the Plan-Do-Study-Act (PDSA) approach to change. The focus of our project was on loss to follow-up at our largest tertiary care hospital, Fletcher Allen Health Care (FAHC). Our baseline data for 2011 revealed a loss to follow-up rate at FAHC of 31%. We implemented many PDSA cycles during the collaborative, focused on two areas of improvement. The first included the FAHC universal newborn hearing-screening program implementing the scheduling of outpatient appointments before the time of discharge for infants who would be leaving the hospital on the weekend. The second PDSA involved VTEHDI staff pulling data



quarterly on infants without a final hearing or diagnostic result and contacting the families and PCPs an additional time. The concentration of both PDSA cycles was for the first half of 2013 and resulted in a 90% improvement in the loss to-follow up rate (31% 2011, 3% first half of 2013). The challenge for FAHC and VTEHDI will be to sustain the change.

Increasing our collaborative relationships with Early Head Start providers, Part C providers, Licensed Midwives, Primary Care providers, WIC providers, Home Visiting Program and the Community Health Teams is a key element for improving loss to follow-up in Vermont. Additionally, it will be essential that VTEHDI to continue to monitor available data closely.

## NEEDS ASSESSMENT

Vermont continues to be one of the more rural states as measured by population density. Our birth rate continues to decrease annually. As a state, we are involved in a refugee resettlement program primarily in the Burlington area, our largest city. Even with the resettlement program Vermont continues to be 93% white non-Hispanic.

- In 2011, Vermont had 5703 in-state births, of which 5,634 (98.8%) were screened.
- There were 119 homebirths in 2011 and 50% were screened in the first year of the midwives being trained to provide OAE screening to their clients. In the first half of 2013 63% of homebirth infants received a hearing screening.
  - 143 of the 5,634 did not pass their final in-hospital screen, and of the 143, 22 passed a follow up hearing screening,
  - 52 parents declined services,
  - 57 families did not respond to phone calls or letters, and
  - 9 infants were diagnosed with hearing loss.
  - 57 of 143 were considered loss-to-follow up (39%). Of the LtFU rate of 39%, 0% were LtD (loss to follow-up for diagnostics) and all 39% were LtRS (loss to follow-up for re-screening)
  - All who were diagnosed with hearing loss were referred to early intervention (0% LtEI, 78% were enrolled in early intervention by 6 months of age).
  - Overall loss to follow-up (LtFU) rate was 39% for 2011.

Our experience with hearing screening suggests several slippery steps on the path from screening to diagnosis and early intervention:

### **From hospital to rescreen to diagnosis:**

We agree wholeheartedly with the NICHQ and AIM project recommendations for strategies to reduce loss to follow-up (scripting the message to parents, identifying a second point of contact for families, verifying identity of the primary care provider (PCP), making the follow-up appointment prior to discharge, reminder calls, making two appointments, fax-back to PCP, fax-back between audiologist and PCP, and obtaining

consent for referral to Early Intervention (EI)). Several of these strategies we already employ because of our care management style approach. However, we note the following areas for improvement: Accurate documentation (of baby names, parent names and parent contact) is critical to communicate follow-up. We contact the hospital nursery; sometimes there is a staff person who can locate missing information. Another strategy is to utilize the information from other points of contact, electronic medical records where available, bloodspot screening, PCP office, WIC, Home Visiting Program, immunization records and birth certificates. The scheduling of outpatient appointments prior to discharge, especially from our largest tertiary care hospital Fletcher Allen Health Care, is a critical issue in our high rate of loss to re-screening. This will be an important quality improvement initiative in a new grant cycle. Half of the infants in Vermont are born at FAHC, but the hospital has limited hearing screening technician hours to meet the screening need. In all other birth hospitals in Vermont, the nursing staff is responsible for the hearing screening of all infants.

Consistent, sensitive, culturally relevant screener-to-parent messages would strengthen the assurance of follow-up. Our program has disseminated to every nursery informational brochures for parents, written by parents and program staff. However, we do not know how thoroughly these are used; in addition, we do not monitor the ongoing training and the actual message giving of each hospital's screening staff. VTEHDI sponsors a one-day conference with screeners and hospitals every two years for updates and discussions. This represents an avenue to introduce consistent, sensitive and culturally relevant messages. Additionally, we have implemented hospital site visits in order to have quality face time with hospital-based screeners. Since the beginning of the last grant cycle (April, 2011), site visits have occurred at all 12 birthing hospitals. Some visits are on going as we help with carrying out quality improvement activities. Additionally, every other year the VTEHDI program hosts an education and training day for screeners

Cross-border communication, reporting, and follow-up issues are significant in New England. Small geographic state size and the location of birth hospitals on the borders contribute to large numbers of residents of one state being born or receiving follow-up services in a neighboring state. At least 10 percent of Vermont resident births are born—and screened—in neighboring states. To assure these babies receive timely and necessary follow-up, the New England states, under the leadership and with assistance of current federal funding sources (CDC and HRSA) have collaborated to forge inter-state data sharing to facilitate the reporting of this information. To date, Massachusetts, Rhode Island, Maine, New Hampshire and Vermont have data-sharing agreements.

Access to a timely, definitive diagnosis, however, is a slippery point along the way. Sleep-deprived ABR in highly skilled pediatric centers is offered only at Vermont's largest tertiary care hospital, Fletcher Allen Health Care in the northwest part of the state, and at Dartmouth Hitchcock Medical Center in Lebanon, New Hampshire, which serves Vermont's southern population. Two other tertiary care centers, each over the border in NY and MA, offer sleep-deprived ABRs. The VTEHDI program in collaboration with the Hearing Advisory Council at the Vermont Department of Health recently approved an ABR protocol for sleep-deprived testing. In order for practices to be on the approved statewide list for VTEHDI for sleep-deprived ABR, the sites must adhere to the protocol when testing infants.

The monitoring and treatment of intervening middle ear disease can delay diagnostic testing and a definitive diagnosis. One of the challenges we face is with our largest pediatric ENT practice at Fletcher Allen Health Care and his understanding and support of best practices with sleep-deprived and sedated ABR testing. Infants and young children associated with this practice have been diagnosed late, as a result of a sleep-deprived ABR not being completed, or a sedated ABR not being completed in the OR after insertion of PE tubes. Our program stresses the importance of ABR testing being completed with bone conduction testing. Currently we are working with the provider and quality department of the hospital to educate on best clinical practices.

The enhancements of the CHHS integrated database and tracking system, has streamlined our reporting processes, data quality assurance functions, and clinical tracking and follow-up for Vermont newborns. PCP providers, Midwives, Early Head Start Providers and Audiologists, after signing a confidentiality agreement, can enter newborn hearing screening results, outpatient screening results or diagnostic hearing testing results directly into the database. VTEHDI is in the process of rolling out the new capabilities of the database to providers.

Areas where improvement is needed:

- Documentation of screening results.
- Documentation of parent/guardian contact information at the hospital level.
- Making outpatient appointments before discharge for all infants;
- Improved parent materials and consistent messaging by screeners;
- Continued individual follow-up care management, in collaboration with the PCP, to assure family connection with rescreening or diagnostic testing.
- Parents and PCPs understanding about the why-when-and-how of diagnostic audiology for babies who do not pass their newborn screens,
- Parent and PCPs understanding about the why-when-and –how of follow-up recommendations for babies who present with hi-risk factors.

### **From diagnosis to intervention:**

Over the last 3-year grant agreement we have experienced a significant improvement in the area for complete and timely reporting of diagnostic results to VTEHDI. This, in turn, has enabled us to assure timely referral into early intervention as well as the completion of medical work up. .

When a baby is re-screened and does not pass, the next step—timely ABR diagnosis—is discussed by VTEHDI staff with the family and the contact information for diagnostic sites is provided. This information is also reported to the baby’s PCP. A release of information form is sent to the diagnostic center for the parents to sign, to facilitate reporting of results back to the program. Currently, we receive reports from diagnostic audiologists by mail and fax. The VTEHDI program is in the process of training our audiology stakeholders on electronically reporting directly into CHHS database.

Vermont’s Children’s Integrated Services Early Intervention (CIS-EI) Program contracts with the Vermont Parent-Infant Program (VTPIP), to provide statewide case management and direct services for infants and toddlers with hearing loss. VTPIP and VTEHDI share a collaborative and contractual relationship. Due to our connection with

VTPIP, we are certain that every baby diagnosed is referred to early intervention. On the other hand, we have inconsistent access to outcomes of referrals, as measured by IFSP dates, and even less information about the utilization of early intervention once a baby is referred. These are areas of needed improvement and increased communication with our Part C partners.

CIS-EI is a unit within the Department for Children and Families (DCF). DCF and VDH are sister departments, both within the Agency of Human Services which is promoting non-categorical and integrated approaches to serving populations. It is an opportune time to forge agreements with Head Start and Part C programs that will enhance services for children.

Areas where improvement is needed:

- Standardized diagnostic reporting, from both in-state and out-of-state centers
- Increased coordination and data sharing between the VTEHDI program and the early intervention programs, including outcomes *after* the referrals are made
- Individual care management, in collaboration with the PCP, to assure family connection with early intervention

## METHODOLOGY

We will undertake a Plan-Do-Study-Act (from NICHQ and the Vermont Agency of Human Resources Agency Improvement Model) for quality improvement process for implementing strategies that will result in a decrease in the loss-to-follow-up rates. We will utilize three already-established advisory workgroups: the existing Hearing Advisory Council and its parent committee; a workgroup of nursery screening managers (which has met every other year since 2003; and the existing monthly meeting of the VDH-AAP-AAFP-MCH group (described in Organizational Information, below).

**Goal 1: Identify and recruit a collaborative team of stakeholders, who will develop an overriding AIM statement for quality improvement measures in reducing loss to follow up in Vermont by October 1, 2014 and who will assess team development throughout the three-year project.**

The VTEHDI program will identify and recruit stakeholders for our collaborative quality improvement team. Members will include the VTEHDI program director, VTEHDI data manager, VTEHDI administrative assistant, VTEHDI project coordinator, a minimum of one pediatric audiologist, a minimum of one parent, a Early Head Start provider VTPIP early intervention coordinator, Vermont's AAP Chapter Champion and a member of a culturally diverse community.

In order for the team to be successful with quality improvement, it will be critical for us to ensure a highly effective/performing team. The VTEHDI program director will coach and mentor the team through the four stages (forming, storming, norming, performing) of team development (Wheelan, 2005). The team development will be assessed through administration of a survey of team participants at each of the development stages.

**Goal 2: Develop an overriding AIM statement for quality improvement measures in reducing loss to follow up in Vermont by August 1, 2014.**

The focus of the Vermont Team during the Learning Collaborative was to reduce loss to follow-up at our largest tertiary care hospital, Fletcher Allen Health Care, which accounts for half of Vermont's birth population. In 2011 the loss-to follow up rate was 31% for the hospital. The collaborative team implemented PDSA cycles, and monitored data in real time through the CHHS database. As a result of the initiatives, loss to follow up at Fletcher Allen was reduced to 3% for the first half of 2013. Currently, the objective of the HRSA grant proposal is to reduce loss to follow up by 5% per year with 2011 loss to follow-up rate serving as the baseline. Given the improvements noted in the first half of 2013, the Vermont team will review baseline data of 2012 and 2013 and develop an overriding AIM statement for Vermont's loss to follow-up population.

**Goal 3: Reduce loss to follow up for Vermont infants by 5% per year for grant years 1, 2 and 3 through the implementation of Plan, Do Study Act (PDSA) Cycles. Baseline data from 2011, 2012 and 2013 loss to follow up rates in Vermont will be compared with 2014 through 2016.**

As a program, we have established strong ties to the audiology community, medical homes, home birth midwives and Early Head Start programs in Vermont, through our advocacy for young children and their families. In building these relationships, we have gifted equipment as well as our time for staff training and education. We believe that, by continuing our present collaborative relationships and pilot projects, we will increase the percentage of infants re-screened in a timely manner thus reducing Vermont's loss to follow-up rate. As part of this proposal we plan to expand collaboration with the WIC program, Home Visiting Program and the Community Health Teams (CHT) at Fletcher Allen Health Care. Additionally, as a result of changes in legislation at the Vermont state level, certified nurse midwives can now provide homebirth services. We anticipate there will be an increase in the Vermont homebirth population, and will include certified nurse midwives in our current pilot project initiatives.

We will continue to follow up with families, in collaboration with the baby's PCP or midwife, to assure that re-screening occurs within the first month. Additionally, we will work to assure that diagnostic testing is completed by 3 months of age for any infant not passing a hearing screening.

Our focus is to decrease our loss to follow-up as compared to 2011 and sustain the changes in loss-to-follow-up evidenced in the first half of 2013, through the support of the HRSA sponsored Learning Collaborative and the Agency Improvement Model at the Agency of Human Services, resulting in meeting the JCIH recommended national standards for screening, identification and intervention.

**Goal 4: Continue to collaborate with early childhood providers including Early Head Start and Part C for years 1 through 3.**

During the 3 years our EHDI program has collaborated with all four Vermont Head Start programs for training and support of objective hearing testing. We will continue to conduct annual outreach/trainings, similar to the hospital site visits. Staff meetings/calls, shadowing and/or mentoring will continue on a quarterly basis with Early Head Start providers. Early Head Start currently shares hearing screening data with the VTEHDI program quarterly VTEHDI has recently enhanced the CHHS database and

Early Head Start providers upon completion of training will be able to enter hearing screening data as soon as the screening is completed on the Vermont Department of Health's website. The plan for this goal is to continue our role with Early Head Start.

We have long collaborated with the Part C program-serving infants with hearing loss, the Vermont Parent Infant Program (VTPIP). VTPIP provides statewide direct service through home visit contact for children who are deaf or hard of hearing, birth to 3 years of age. VTPIP is the single point of entry for early intervention referral services in Vermont. The VTPIP Coordinator has served on the HRSA sponsored Learning Collaborative and the Agency Improvement Model Team at the Vermont Department of Health. Moreover the coordinator serves on the Vermont Department of Health's Hearing Advisory Council and is a member of the Board of Director for Vermont Hands & Voices. In addition to the VTPIP Coordinator's collaborative role with VTEHDI, we have used funding from our HRSA grant to help VTPIP with attending the national EHDI meeting, new initiatives, support of a parent advisor, and activities to establish a Hands and Voices chapter for Vermont. We feel it is important to continue funding in a collaborative model for reducing loss to follow up. The new initiatives with the VTPIP will include the Coordinator's role on the Vermont Collaborative Team for quality improvement with loss to follow up, attendance of parent advisors at diagnostic appointments for children birth to 3, to support families and assure follow-up, implementation of the early intervention checklist introduced by NICHQ during the most recent learning Collaborative, continued involvement with the Vermont Chapter of Hands and Voices, and support of a parent advisor to the Vermont Collaborative Team.

The above goal will allow us to continue to collaborate and expand our relationship with the VTPIP. Additionally, this goal will allow our program to explore and expand our relationship to the regional (generic) VT Part C programs. This expansion will help us be able to collect more comprehensive outcome data, including dates of IFSP sign off and enrollment into VT's regional Part C programs.

The Childhood Hearing Health System Database (CHHS) web-based patient profile will be used to populate the reports we provide back to the programs. Early Head Start providers and the VTPIP Coordinator will have read and write access to CHHS.

The program director, the data administrator, and project coordinator will carry out these objectives and their associated activities.

**Goal 5: VTEHDI will identify and implement a plan for financial sustainability for the program by the end of year 3.**

The VTEHDI program was established in 2003 and the majority of financial support currently comes from grant funding through HRSA and CDC. During the next grant cycle we propose to meet with the leadership at the Vermont Department of Health and Fletcher Allen Health Care, to identify and implement a proposal for sustainability of VTEHDI.

The program is highly successful in tracking and surveillance of Vermont's infants in the realm of hearing screening, identification of hearing loss and entrance into early intervention. Additionally, the program goals and objectives are aligned with the national goals for universal newborn hearing screening as well as the Vermont Department of Health's 2020 goals.

The Vermont Department of Health is currently preparing for an accreditation site visit scheduled for March 20-21, 2014. The accreditation process has challenged the Health Department to think critically about the way it does business, allowed staff to identify processes and programs where improvements are needed, and strengthened the department's culture of continuous quality improvement. The Public Health Accreditation Board's standards and measures provide a means for the department to continually assess its effectiveness in delivering the ten essential public health services. Funding from this grant will continue to support our quality improvement efforts relating to newborn screening and follow up through ongoing tracking and surveillance (Domain 1). Additionally, the funding will enhance our ability to translate materials relating to the importance of hearing screening in infants in order to provide accurate, accessible and actionable information to the various communities we serve (Domain 3).

## WORKPLAN

The staff of the project will include the VTEHDI program director, VTEHDI project coordinator, staff audiologist, data manager, administrative assistant and newborn screening chief

**Goal 1: Select and recruit a collaborative team of stakeholders for quality improvement measures in reducing loss to follow-up in Vermont by October 1, 2014  
Coach, mentor and foster team development years 1 through 3.**

Objective 1.1 Identify and recruit stakeholders to participate in a collaborative with the VTEHDI program for reducing loss to follow-up by May 1, 2014.

We will measure the successful completion of the objective by having a list of team members and signed memorandum of agreements with all participants 2010 and 2011.

Who/How: The VTEHDI program director will:

- Contact stakeholders and invite participation
- Develop memorandum of agreement (MOA) form
- Have participants sign MOA
- Develop a roster of participants to the Vermont Collaborative Team for QI

Objective 1.2 Hold the first meeting of the collaborative team by June 30, 2014 and establish a formal team meeting schedule by August 1, 2014.

We will measure the successful completion of the objective by documenting the formal invitation for the initial collaborative meeting and instituting a calendar with the collaborative formal meeting schedule.

Who/How: The VTEHDI administrative assistant will:

- Schedule first meeting and send invitations.
- Schedule meeting space.
- Develop calendar for formal meeting schedule.

Objective 1.3 Creating the Effective Team: coach, mentor and build a highly performing collaborative team.

We will measure our success by becoming a highly effective performing collaborative team. The characteristics of this stage of development will be documented in the member checklists.

Who/How: The VTEHDI program director, in collaboration with the Vermont Collaborative team for QI, will:

- Document stages of development (forming, storming, norming and performing).
- Administer member checklists at each stage of team development.
- Develop and administer satisfaction survey annually for years 1 through 3.
- Review member checklist and survey information.
- Disseminate results to team and address challenges

**Goal 2: Develop an overriding AIM statement for quality improvement measures in reducing loss to follow up in Vermont by August 1, 2014**

Objective 2.1: The Vermont Collaborative team will identify an overriding AIM statement for quality improvement measures in reducing loss to follow-up by August 1, 2014.

We will measure our success by developing and documenting an AIM statement for Vermont.

Who/How: The VTEHDI Collaborative Team in conjunction with our Hearing Advisory Council will:

- Review 2012 and 2013 loss to follow-up data
- Develop AIM statement for Vermont

**Goal 3: Reduce loss to follow up for Vermont infants by 5% per year for grant years 1, 2 and 3 through the implementation of Plan, Do Study Act (PDSA) Cycles. Baseline data from 2011, 2012 and 2013 loss to follow-up rates in Vermont will be compared with 2014 through 2016.**

Objective 3.1: Develop PDSA cycles for scheduling all outpatient appointments of infants who have not passed a hearing screening prior to discharge at the 12 birth hospitals in Vermont by the end of year 1.

We will measure our success by documenting PDSA cycles with results.

Who/How: The Vermont Collaborative Team will:

- Develop PDSA Cycles for quality improvement using small tests of change.
- Evaluate PDSA cycles and expand or revise.
- Produce quarterly hospital report cards reflecting loss to follow-up rate.
- Produce quarterly CDC data reports from the Childhood Hearing Health System (CHHS) database part of the Vermont Department of Health's fully integrated database.



Objective 3.2: Review and update VTEHDI policy and procedures based on PDSA cycle feedback for care management of infants not passing a hearing screening throughout the grant agreement.

We will measure our success by documenting policy and procedure changes and the effects on our loss to follow up rate.

Who/How: VTEHDI program director and project coordinator in collaboration with the Vermont Collaborative Team for Quality Improvement and the Hearing Advisory Council will:

- Develop PDSA Cycles for quality improvement using small tests of change.
- Evaluate PDSA cycles and expand or revise.
- Update policy and procedures for care management based on PDSA feedback.

Objective 3.3: Foster continued collaboration with pilot sites including primary care and homebirth midwives: years 1 through 3.

We will measure our success by documenting the percentage of loss-to follow-up infants in the pilot site for years 1 through 3 and comparing to our baseline data 2011, 2012 and 2013.

Who/How: VTEHDI program director, VTEHDI project coordinator and VTEHDI data manager.

- Mentor, educate and support OAE screening in PCP and homebirth midwives pilot sites.
- Communicate with PCP and midwives to ensure timely hearing rescreening.
- Produce quarterly Reports for pilot sites from CHHS database identifying infants requiring a rescreening for hearing.
- Train and coach providers to electronically report hearing screening data directly into CHHS.
- Provide quarterly newsletter entitled “Tips and Hints.”

Objective 3.4 Collaborate with pediatric audiologists serving Vermont’s infants for timely and complete diagnostic evaluations years 1 through 3.

We will measure our success by comparing real time data from CHHS to the JCIH national standards (screen by 1 month, diagnose by 3 months, intervention by 6 months) for years 1 through 3.

Who/How: VTEHDI program director and staff audiologist in collaboration with the Vermont Collaborative Team and Hearing Advisory Council.

- Develop PDSA cycles for small tests of change for quality improvements, evaluate and expand cycles as appropriate.
  - Introduce NICHQ monthly Audiologist checklists to all pediatric diagnostic testing facilities.
  - Implement electronic reporting of diagnostic testing directly into CHHS database

Objective 3.5: Expand relationships with WIC, Home Visiting Program and Community Health Teams by the end of year 2.

We will measure our success by developing a successful partnership and documenting infants in our loss to follow-up cohort who are screened as a result of collaboration among the groups.

Who/How: The program director, project coordinator, and data manager, in collaboration with the Vermont Collaborative Team, will:

- Develop PDSA cycles for small tests of change for quality improvements.
- Learn about WIC, Home Visiting Program and Community Health Teams can support reducing loss to follow-up.
- Evaluate the level of collaboration VTEHDI can have with this group of stakeholders in reducing loss to follow-up.
- Identify need for direct clinical services from VTEHDI project coordinator and staff audiologist.

Objective 3.6: Attend quarterly meetings with the New England border states to reduce loss to follow-up of infants born in one state and screened in another: years 1 through 3.

We will measure our success through meeting minutes and documentation of sharing screening data through our cross border agreements.

Who/How: program director will:

- Attend New England Conference calls

#### **Goal 4: Strengthen and expand collaborative relationships with early childhood programs including Head Start and Part C.**

We will continue to support hearing screening, training and provide education to Part C and Early Head Start providers.

Objective 4.1: Support hearing screening, training, education and mentoring in Early Head Start and Part C programs: years 1 to 3.

In collaboration with the National Center for Hearing Assessment and Management's (NCHAM) ECHO initiative, our program will continue to support, educate, train and expand services with Head Start and Part C providers.

We will measure our success through documentation of training activities and data sharing documentation.

Who/How: The VTEHDI project coordinator and data manager, in collaboration with ECHO, will:

- Monitor practices to ensure quality implementation of hearing screening services.
- Evaluate timeliness of data shared and examine effectiveness of data sharing in identify children with late onset hearing losses and loss to follow-up from newborn screening.
- Move from fax-back referral forms and quarterly reports to electronic reporting by providers into the CHHS database.

Objective 4.2: Continue funding and relationship with the Vermont Parent Infant Program (VTPIP) in years 1-3.

VTPIP is the core service meeting the Joint Committee on Infant Hearing position principles for the foundations of an effective EHDI program, including "... a single point of entry into an intervention system appropriate to children with hearing loss is optimal"

...and services are... “conducted by qualified professionals who understand the needs of deaf and hard of hearing children and their families.” VTPIP puts parents in touch with the professionals who help them navigate Vermont’s early intervention system. The Coordinator of the VTPIP program served on the HRSA NICHQ Learning Collaborative and the VDH Agency for Improvement Model. Additionally, the coordinator will be participate on the Vermont Collaborative Team for quality improvement. VTPIP staff provides comprehensive information about hearing loss addressing such issues as:

- Newborn hearing screening and its impact on families
- Impact on language & communication development
- Models of communication methods and language choice
- Auditory skill development
- Educational options
- Audiological Testing, amplification and technology
- Deaf Culture
- Emotional support & parent networking.

VTPIP staff also collaborates with local CIS-Early Intervention Part C offices to ensure the IFSP adequately addresses the needs of these children and families, including coordinating training events to ensure that EI staff remain current with best practice for services to this population.

VTPIP requires strengthening in its capacity to reach the new goals of this project, including outreach to Head Start and education and mentoring for families whose young children have hearing loss. In addition, early identification and diagnosis are leading to earlier utilization of amplification and cochlear implants. VTPIP must be the premier source of specialized early intervention for this new/growing population.

We will measure our success by comparing our data from CHHS for years 2014 to 2016 with the JCIH national standards.

Who/How: The VTEHDI program director, in collaboration with VTPIP Coordinator, will:

- Support timely and appropriate early intervention services for children birth to 3 years of age identified with permanent hearing loss.
- Expand the parent infant advisor role.
- Continue support of a Vermont Hands and Voice Chapter.
- Support trainings and education for VTPIP providers.
- Participate in the Vermont Collaborative Team for quality improvement in reducing loss to follow-up.
- Establish the Early Intervention Monthly Checklist
- Participation at diagnostic audiology appointments by Coordinator VTPIP or a parent advisor.

**Goal 5: VTEHDI will identify and implement a plan for financial sustainability for the program by the end of year 3.**

The VTEHDI program director in collaboration with the newborn screening chief and leadership at CSHN and MCH.

Objective 5.1: Identify a team of stakeholders at the Vermont Department of Health and develop a sustainability plan for VTEHDI by the end of year 3.

Who/How: The VTEHDI program director, in collaboration with newborn screening chief and leadership at Children with Special Health Needs (CSHN), will:

- Identify key stakeholders
- Develop long term VTEHDI budget
- Set up meeting schedule with sustainability team
- Develop plan for sustainability
- Implement plan by the end of year 3.

## RESOLUTION OF CHALLENGES

The CDC-funded CHHS integrated database: VTEHDI has successfully developed and instituted enhancements to the data system, the Childhood Hearing Health System (CHHS), with funding from the Centers for Disease Control. CHHS is part of an integrated database, the Secure Personal Health Information Exchange (SPHINX) along with the electronic birth/death registries, immunizations registry, dried blood spot and lead screening. SPHINX also provides primary care providers and other external users, with approved permissions, the ability to access, read and enter data on the web-based Patient Health Profile. This profile contains information from each of the programs listed above, including hearing screening results. VTEHDI is also receives electronic submission of hearing screening results through CHHS from multiple hospitals

The Medical Home and the delicate balance of guidelines/protocols and patient-physician autonomy: All Vermont hospitals are offering outpatient hearing screening. The previous HRSA grants enabled collaboration between the medical homes and VTEHDI by offering OAE screeners to PCP's in regions where we are seeing the greatest number of loss-to follow up. Promotion of a uniform hearing screening protocol and recommendations for the medical work-up of congenital hearing loss by VTEHDI may be perceived, by PCPs and ENTs, as interference. The HRSA grants encouraged collaboration and communication between the medical home and VTEHDI. Additionally, through the promotion by VDH of "The Provider Toolkit," PCP's have a set of guidelines, tools outlining recommendations for early periodic screening.

Diagnostic ABR is more accessible now in Vermont but still requires many families to travel long distance for the service. We have limited pediatric sites in the state. Fletcher Allen Health Care provides these services to Vermont families in the upper half of the state and Dartmouth Hitchcock Hospital in the lower half of the state.

High Referral rates at Discharge at FAHC: We continue to struggle with the high referral rates at FAHC, our largest tertiary care hospital in Vermont. This issue is complicated and stems from two distinct areas. The first factor is early discharges prior to 24 hours of age. The second area of concern is that technicians are hired on a per diem basis to conduct hearing screening. They are available only 4 hours in the morning, competing with other providers who also want to examine babies and talk to parents. In all other Vermont hospitals nursing provided the screening services allowing for more flexibility in screening infants prior to discharge. Nursing at FAHC is unionized and not willing to take on the responsibility of hearing screening.

The VTEHDI program: VTEHDI is a lean program and depends upon highly specialized professionals, audiologists with pediatric training and experience for staffing. Seven percent of the dried bloodspot newborn screening fee charged to birth hospitals by the Vermont Department of Health is used to support VTEHDI costs. Additionally, the MCH Director is assessing the need for Title V funding to support the day-to-day activities of EHDI. Staff turnover has been infrequent, but when it happens, its impact is powerful and difficult.

Barriers to reporting: Interstate agreements have been signed between Maine, Massachusetts, Rhode Island, New Hampshire and Vermont. New York has yet to be signed and implemented. Nationally, there continues to be confusion about the finality of the barrier to communication created by FERPA. The agreements are a tool to improve reporting, but they are not the only tool. Individual care planning, personal contact with families to support them through the screening-diagnosis-early intervention sequence, can also achieve improved loss-to-follow-up rates and improved documentation.

State positions: We will continue to contract with FAHC (Fletcher Allen Health Care, UVM's teaching hospital), Department of Community Health Improvement, for the VTEHDI program director, project coordinator, administrative assistant and staff audiologist. Administrative support for VTEHDI, data analysis and a new staff position will come under the purview of the Vermont Department of Health. The collaborative relationship between Vermont Department of Health and Fletcher Allen Health Care has worked exceedingly smoothly for many years.

## EVALUATION AND TECHNICAL SUPPORT CAPACITY

The VTEHDI program is currently full staffed with Linda Hazard (Program Director), Stacy Jordan (Project Coordinator), Ryan Corry (Staff Audiologist), Janet Fortune (Data Manager), Patricia Thompson (Administrative Assistant) and Cynthia Ingham (Newborn Screening Chief). The program also collaborates with the statistics unit of the Division of Epidemiology, including the MCH data chief and the Birth Information Network director. EHDI program staff has initiated an on-going collaborative group of all users within the SPHINX system so that issues of overlap and mutual concern can be addressed consistently.

## ORGANIZATIONAL INFORMATION

Applicant organization: Vermont's Children with Special Health Needs (CSHN) program. It is the mission of CSHN to promote the well being of Vermont children with developmental and special health care needs. Our mission is consistent with the Healthy People 2020 goals of assuring that "children with special health care needs have access to a medical home," and that all "states...have service systems for children with special health care needs." CSHN provides family-centered, community-based, coordinated services for Vermont children with special health needs and their families through direct services (Child Development Clinics and Craniofacial Clinics), care coordination family support, and system-building activities. The newborn screening program within CSHN is responsible for the dried blood spot, metabolic and universal newborn hearing screening programs. The program provides oversight to ensure all newborns are screened, and that

follow-up care is provided to all newborns that have had positive screens. CSHN pediatric nurses and medical social workers are based in regional offices, and are expanding to direct collaboration with pediatric Medical Home practices. Staff is involved in care planning and coordination, including transitions from one care setting to another. CSHN also oversees the Medicaid Personal Care Services program, the Medicaid Hi-tech program, and the Children's Palliative Care program. CSHN, the applicant organization and Title V CSHCN program, is a unit within the Division of Maternal and Child Health, VT Department of Health, Agency of Human Services (AHS).

Cultural Competence: Every AHS employee and major contractor is required to complete an online training course in cultural competence. Every CSHN employee and the EHDI program staff have completed this coursework successfully. In addition, the VT AHEC has just made available a Vermont-specific resource and practice document about cultural and ethnic groups in Vermont.

Collaboration with Bloodspot screening: The newborn screening program is the organizational unit within CSHN overseeing both hearing and bloodspot screening. A single administrative structure interacts with hospitals and nurseries around these efforts. Both programs work closely with their over-the-border counterparts (in NH, NY, and MA) for babies transferred to or born in one state but living another. Comprehensive intervention and support for VT babies identified through both screening programs is provided through CSHN.

Key Collaboration with AAP: VDH, including CSHN, collaborates closely with primary care providers through several projects and relationships with the VT Chapter of the AAP, and the VT AAFP. Monthly meetings of the AAP executive committee and AAFP president, with the VDH MCH director, also a pediatrician, are held with VDH MCH leadership to address child health care and systems issues. The EHDI program has participated in AAP continuing education efforts, and has sought advice from AAP on EHDI protocol and program needs. The CSHN medical director and Child Development Clinic director (Carol Hassler, MD) who oversees clinical aspects of newborn screening programs is also the AAP EHDI Chapter Co-Champion for Vermont. Her supervisor, Breena Holmes, MD, is the MCH director and past vice president of VT AAP.

Early Intervention: CSHN social workers staff each of the 12 regional Part C programs. The specific early intervention team for children with hearing loss, VT Parent Infant Program of the VT Center for the Deaf and Hard of Hearing, continues to partner with CSHN/EHDI in direct services to young children and in creating continuing education programs for staff.

Legislation: Vermont does not have a law requiring hospitals to perform newborn screening. VDH has a statutory responsibility (18 VSA chapter 3 section 115 (b) (3)) for "early case finding" on which its newborn screening activities are based. There are newborn screening regulations, which give VDH responsibility for assuring that newborns are screened and which permit charging a fee to hospitals. Since the mid 1960's, Vermont's birthing hospitals have accepted the responsibility for collecting and shipping dried bloodspot screening specimens to the processing laboratory. Bloodspot results, however, are reported to VDH by the laboratory with which the state contracts to process the samples. Hospitals have also willingly undertaken the hearing screening of their newborns. Hospitals all report hearing screening findings, at this time and the

expectation is expanding to include audiologists who ultimately make the diagnosis of hearing loss as well.

References:

Wheelan, Susan A.(2005). *Creating Effective Teams*. Sage Publications.