

**Reducing Loss to Follow-Up After Failure to Pass  
Newborn Hearing Screening  
New Hampshire Early Hearing Detection and Intervention Program**

**Program Narrative**

**I. Introduction**

Developmental science shows that a child's earliest experiences lay the foundation for formative brain development, establishing a sturdy or fragile base for lifelong health, behavior, and learning. Providing young children with a healthy start, strong family support, and positive early learning experiences is essential for ensuring an environment in which each child can reach their full potential.

The brain is the true organ of hearing – the ears only transmit sounds to the brain. Babies born with hearing loss are not starting from the same point as a child with typical hearing. The 2011 American Academy of Audiology Childhood Hearing Screening Guidelines state that hearing loss is the most common developmental disorder identifiable at birth and under-identification and lack of appropriate management of hearing loss in children has broad economic effects as well as a potential impact on individual child educational, cognitive and social development.

Infant brains must be exposed consistently to meaningful sounds in order for auditory neural pathways to develop. When a baby is born with a hearing loss, this process of developing language can be delayed. Through early detection of hearing loss and intervention, delays can be prevented or reduced.

The New Hampshire Early Hearing Detection and Intervention (EHDI) Program is pleased to submit this application for funding to reduce the loss to follow-up after failure to pass newborn hearing screening. The EHDI Program is housed within the New Hampshire (NH) Title V program in the Maternal and Child Health Section (MCH) of the Bureau of Community Health Services, Division of Public Health Services, NH Department of Health and Human Services (DHHS). The NH EHDI Program began its work in newborn hearing screening in 2000. Over the past thirteen years, the program has matured and is well positioned to continue the current newborn hearing screening activities.

The State of New Hampshire shares boundaries with Canada to the north, Maine and the Atlantic Ocean to the east, Vermont to the west and Massachusetts to the south. New Hampshire is one of the three northern New England states, which along with Maine and Vermont, are more rural than the southern tier: Massachusetts, Connecticut and Rhode Island. Approximately 37% of the population and 84% of the landmass in New Hampshire is considered rural. The majority of New Hampshire towns are considered non-urban or rural, with urban and near urban areas located in the southeast and south central regions and primarily rural areas in the western, central and northern sections. The three most urban areas are Manchester, Nashua and Concord, all located in the State's southern third. In contrast, the White Mountain National Forest separates the northernmost rural area from the rest of the state. New Hampshire citizens in rural

communities face geographic barriers to health care such as lack of transportation and increased travel time to health care providers and hospitals<sup>1</sup>.

The NH EHDI Program has a full time EHDI Program Coordinator, a half time Nurse Specialist, a part-time Consulting Audiologist and a part-time Follow-up Coordinator (family advocate), who was added in 2007 to reach out to families of infants referred for diagnostic testing. The program coordinator is a nurse who previously worked in several maternal and child health care in hospitals, visiting nurse agencies doing home visits or well child clinics, and, most recently, an Early Head Start program. The Nurse Specialist previously directed the New Hampshire Department of Health & Human Services Preschool Vision and Hearing Screening Program. She is responsible for monitoring all entries into the data tracking system to assure that all infants are entered into the tracking system by the birth hospital newborn hearing screening staff by matching tracking system entries with extracts of birth certificate data. She also assures that all hearing screening results are entered into the system before the infant is two weeks old. The Consulting Audiologist provides education and support to the audiologists who test infants. She also provides training to the staff at the birth facilities. This includes all hospital newborn hearing screening staff and the certified lay midwives at three freestanding birth facilities. The Follow-up Coordinator uses the tracking system to find all infants who did not pass their final hearing screening and reaches out their parents by letters or telephone calls to assist them in obtaining and completing diagnostic testing before the infant is three months old.

## **II. Needs Assessment**

New Hampshire consistently ranks among the top states in the nation for many indicators or predictors of child well-being. In the 2013 KIDS COUNT® Data Book, the Annie E. Casey Foundation ranked New Hampshire “First in the Nation” for trends in child well-being. However, rank alone cannot paint a complete picture of how youth in New Hampshire are faring. In New Hampshire, there are two areas of concern: an overall decline in child health and a growing poverty rate. The Data Book reports that in 2011 the child poverty rate was at 11 percent in New Hampshire. From 2009 to 2011, the number increased from 31,000 to 33,000 children. In 2011, there were 65,000 New Hampshire children living in a household where both parents are unemployed.

It is clear that socioeconomic status, maternal demographic data, and healthcare status are inextricably linked. When poverty and poor health are present, children are at risk for a host of life-long adverse outcomes. However, there are measures that can be taken to minimize poor outcomes. While proportionally fewer children in New Hampshire face these risks compared to other parts of the country, there are still geographic, racial, ethnic and economic disparities that cannot be ignored. Governor Maggie Hassan’s press release from June 2013 cited that “the number of children in New Hampshire without health insurance remains too high at 10,000 children”.

The population in New England and New Hampshire in particular, is changing. The National Endowment for the Humanities states that approximately 3000 refugees from 31 countries settled in the southern New Hampshire, Nashua–Manchester metropolitan area between 2000 and 2007. The minority population in this area has increased by 53 percent in the past decade. As might be expected based on the differing racial and ethnic proportions in

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<sup>1</sup> NH DHHS DPHS Rural Health and Primary Care section, 2010

younger age groups, births in New Hampshire are becoming more ethnically and racially diverse.

The percentage of births to racial and ethnic minority groups has more than doubled over the past decade. In 2008 and in 2009, over 17 percent of resident births were to parents where at least one reported a race/ethnicity other than non-Hispanic white, compared to only 7.6 percent of births in 1998. The data from Table 1 on maternal race for 2012 indicates that 12% of the births in NH were to mothers listing their race as other than white non-Hispanic. Health care providers in New Hampshire have responded to these changes by offering more options to meet the needs of parents from minority groups. Several New Hampshire organizations provide translation services and interpreters for clients who use other languages, including American Sign Language.

**Table 1: Data on Maternal Race from 2008 to 2012**

Maternal Race	Year of Infant Birth					Total
	2008	2009	2010	2011	2012	
White (Not Hispanic)	12,054	11,886	11,567	11,485	11,067	58,059
White (Hispanic)	100	106	116	126	152	600
White (Ethnicity Unknown)	96	53	56	101	48	354
Black or African American (Not Hispanic)	180	182	181	191	176	910
Black or African American (Hispanic)	7	9	7	11	8	42
Black or African American (Ethnicity Unknown)	1	2	1	2	2	8
Asian	444	443	418	442	380	2,127
Native Hawaiians & other Pacific Islanders	12	12	9	11	7	51
American Indian & Alaska Natives	21	15	9	18	20	83
Unknown	71	55	62	73	84	345
Other	644	626	606	620	634	3,130
Total	13,630	13,389	13,032	13,080	12,578	65,709

The NH Early Hearing Detection and Intervention (EHDI) program staff has made significant progress in achieving the national goals for newborn hearing screening: complete hearing screening by 1 month of age, complete diagnostic testing by 3 months of age, and enroll in early intervention by 6 months of age. The hearing screening rate for all infants born in NH during 2012 was 97.6%.

The staff at all twenty New Hampshire hospitals with birth units and three freestanding birth facilities currently offer newborn hearing screening to all families. During 2012, 12,281 infants (97.8 %) of the infants born in hospitals had their hearing screened. An additional one hundred six (106) infants had a reason for not having a newborn hearing screening: parental refusals (19), deceased infants (37) or transferred out of state (42). Eighty-seven (87) infants had neither hearing screening results nor documentation of any reason not to screen. At freestanding birth centers 65% (64 of the 98) infants born had newborn hearing screening results documented in the tracking system for 2012.

The remarkable progress made by our hospitals to institute early hearing screening has been completely voluntary; New Hampshire does not have legislation requiring newborn hearing screening. In December 2005, the New Hampshire Joint Legislative Committee on

Administrative Rules adopted rules that require anyone conducting newborn hearing screening in the state to report the results to the NH EHDI Program. The rules also require that facilities allow periodic on-site review of newborn hearing screening activities by EHDI staff for quality assurance purposes. The EHDI staff makes site visits.

During the past seven years of site visits, the EHDI staff worked with hospital staff to improve newborn hearing screening programs with quality improvement reports based on set performance measures. The EHDI staff reviewed the policies and procedures of every newborn hearing screening program, conducted performance reviews for every facility and requested changes as needed to improve the hearing screening programs. In addition, site visits were made to meet new program managers, to discuss facility policies and performance measures and to suggest improvements to their newborn hearing screening programs. When indicated or requested by a facility, the EHDI staff conducted hearing screener training sessions.

The EHDI staff: Program Coordinator, Program Specialist, Consulting Audiologist and Follow-up Coordinator, convened and met with a group of hospital staff members to address and develop a message for families regarding newborn hearing screening. A flow sheet was developed for hospital staff members conducting hearing screenings as to what to say to families regarding screening results. The EHDI staff continues to monitor the messaging to families especially when an infant fails their hearing screenings. The expected outcome is to improve the numbers of families that follow through with obtaining diagnostic testing for their infants.

### **Demographics**

An estimated 1.3 million people live in New Hampshire with 12,578 births occurring in 2012. The geography of New Hampshire is such that mountains, rivers, and lakes create barriers that make transportation and reaching healthcare services difficult for most of the state. Many residents of northern New England (Maine, New Hampshire and Vermont) support personal choice and a natural and personalized experience. As a result, about 200 infants (averaging 1.6% of the annual births) are planned births in freestanding birth facilities, or at home without the policies and practices common in institutions. Certified lay midwives are approved by New Hampshire and attend births at home and in birth facilities. Most families using certified lay midwives are willing to have blood spot testing and newborn hearing screening as long as they are not required to go to a hospital.

### **Hospital Newborn Hearing Screening**

Currently, 20 New Hampshire hospitals offer birthing services. During the past ten years this number has decreased from 24 to 20 due to closures of birth units in several small hospitals (see map of birthing facilities in Attachment 6). Each New Hampshire hospital with birth facilities purchased their own newborn hearing screening equipment. The majority of infants, over 99% each year, are born in one of the twenty New Hampshire hospitals with birth facilities (See Table 2). The hospitals' birth unit staff are completing hearing screenings for newborns and recording the screening data in the New Hampshire tracking system.

**Table 2: Births Occurring in NH from 2008 to 2012**

Birth Location (Hospital Name or Other Birth Place Type)	Year of Infant Birth					Total
	2008	2009	2010	2011	2012	
Alice Peck Day Memorial Hospital	275	276	282	275	315	1,423
Androscoggin Valley Hospital	120	98	130	137	109	594
Catholic Medical Center	898	810	917	1,142	1,081	4,848
Cheshire Medical Center	520	511	491	464	469	2,455
Clinic/Doctor's Office	0	0	1	1	2	4
Coastal Family Birth Retreat	17	24	29	24	28	122
Concord Birth And Wellness Center	26	17	15	20	18	96
Concord Hospital	1,351	1,311	1,309	1,332	1,310	6,613
Cottage Hospital	80	81	78	86	91	416
Dartmouth-Hitchcock Medical Center	1,152	1,184	1,166	1,117	1,140	5,759
Elliot Hospital	2,248	2,218	2,084	1,867	1,811	10,228
Enroute	13	8	6	6	14	47
Exeter Hospital	748	756	702	702	711	3,619
Frisbie Memorial Hospital	372	436	395	401	379	1,983
Home-Planned	111	115	107	109	90	532
Home-Unplanned	10	19	14	16	22	81
Huggins Hospital	92	71	1	0	0	164
Lakes Region General Hospital	489	417	448	389	357	2,100
Littleton Regional Healthcare	316	294	297	310	274	1,491
Memorial Hospital	211	218	234	239	252	1,154
Monadnock Birth Center	6	8	11	11	6	42
Monadnock Community Hospital	343	348	318	330	317	1,656
New London Hospital	1	0	0	0	0	1
Other/Unknown	1	1	1	4	4	11
Parkland Medical Center	278	259	203	204	176	1,120
Portsmouth Regional Hospital	655	570	606	606	550	2,987
Southern NH Medical Center	1,465	1,414	1,388	1,487	1,356	7,110
Speare Memorial Hospital	137	187	175	171	169	839
St. Joseph Hospital	492	548	496	463	485	2,484
The Birth Cottage-Milford	38	41	34	55	46	214
Upper Connecticut Valley Hospital	0	0	0	1	0	1
Valley Regional Hospital	221	149	174	174	8	726
Weeks Medical Center	24	0	0	0	0	24
Wentworth-Douglass Hospital	920	1,000	920	937	988	4,765
<b>Total</b>	<b>13,630</b>	<b>13,389</b>	<b>13,032</b>	<b>13,080</b>	<b>12,578</b>	<b>65,709</b>

Nearly 99% of the infants born in hospitals had newborn hearing screening, in each of the past four years. Approximately 97% of all infants born in New Hampshire had a newborn hearing screening the same time period. Infant deaths and transfers to out-of-state hospitals account for about 1% of the infants born in New Hampshire. It is probable that infants transferred to neighboring states are screened for hearing loss, but the results are not always reported to the NH EHDI program. The newborn hearing screening programs in Maine, Massachusetts, New Hampshire and Vermont developed an agreement to report newborn hearing screening results for infants who are residents of a border state. The agreement was approved in all four states.

New Hampshire's statewide final refer rate is 2%, well within the JCIH's recommended refer rate of 4% or less. Based on an average number of 13,000 New Hampshire annually, approximately 260 babies statewide may be referred for diagnostic audiology testing per year.

### **Missed Newborn Hearing Screening**

Approximately 2% of the births in New Hampshire (113 in 2012, 218 in 2009, 219 in 2008 and 166 in 2007) occurred at home or in freestanding birth centers. The certified lay midwives attending these births recommend newborn hearing screening to their clients. The midwives report that their clients are reluctant to obtain newborn hearing screening at local hospitals. The EHDI Program purchased a handheld otoacoustic emissions (OAE) screener for use by certified lay midwives in January 2009.

The two midwives at this freestanding birth center use this OAE equipment to offer hearing screening to all families using their facility. Only one family refused newborn hearing screening in 2012. These midwives also offered newborn hearing screening to all families of infants born at home or in other birth facilities, but no families have come to their facility. In attempt to screen more of the babies born at free standing birth centers, several training sessions have been offered to the midwives along with the provision of additional OAE screening equipment for the other three freestanding birth centers to reduce the number of infants who are not offered newborn hearing screening. The plan is for other midwives who do not work in birth centers to refer their clients to a freestanding birth center for newborn hearing screening. Since the OAE screening equipment was placed, the EHDI staff is evaluating if additional resources are needed for other geographic locations in New Hampshire.

Although the purchase of equipment in 2007 for one freestanding birthing center had local impact, it was determined that certified lay midwives throughout the state needed training and support to perform newborn hearing screening and the ability to be able to offer hearing screening to the families in their care. In 2012, 65% (64 of the 98) infants born at freestanding birth centers had newborn hearing screening results documented in the New Hampshire EHDI tracking system. Prior to 2009, when the first OAE screener was purchased, few if any infants born outside of a hospital setting received newborn hearing screening.

### **Decreasing Lost-To-Follow-Up**

The EHDI Program staff developed Newborn Hearing Screening Performance Measures to report on quality assurance for each hospital program. Performance measures are used to monitor the strengths and weaknesses of each hospital's newborn hearing screening program. Every newborn hearing screening program manager is encouraged to use their performance measures as a quality indicator. In 2007, hospital program managers submitted their newborn

hearing screening protocols for review by the EHDI staff. After the EHDI staff reviewed each protocol, they were returned with comments and suggestions for improvement. Many of the protocols submitted need to be updated to include new recommendations from the 2007 Joint Committee on Infant Hearing Position Statement. The EHDI staff discusses the individual hospital performance measures during site visits to give additional feedback and suggestions.

Two years ago, the EHDI staff met with representatives from hospital newborn hearing screening programs. The group used quality improvement strategies developed by the National Initiative on Child Health Quality (NICHQ) to develop a message for parents of infants who refer on their final hearing screening. After much discussion, multiple cycles to test small changes, and refining the message, the messages were finalized and distributed to all newborn hearing screening programs. The number of infants referred to diagnostic evaluation improved from 2008 (159 infants) to 2012 (286 infants).

The performance measures for each year from the EHDI tracking system are used to calculate the numbers of infants lost to follow-up in New Hampshire between hospital screening and rescreen, between rescreen and audiologic testing, and between audiologic diagnosis and entry into early intervention services. The activities of the EHDI staff and hospital staff have reduced loss-to-follow-up between hearing screening and rescreening. However, the loss-to-follow-up between rescreening and diagnostic testing remains high. During the next three years, the EHDI staff will focus on several quality improvement strategies: making rescreening and audiologic appointments for the infant at hospital discharge, using telephone reminders for appointments and scheduling two audiology appointments two weeks apart. This should lead to more infants receiving diagnostic testing than the 66.9 % (180/269) who did in 2011.

There is a critical shortage of qualified audiologists, especially pediatric audiologists, both nationally and in New Hampshire. Without timely access to high quality diagnostic services, the screening process and family support services are inadequate to meet the needs of infants with potential hearing loss. Nationally, audiologists are facing a mandate for doctoral level preparation of all audiologists. Compounding this issue is the fact that infant or pediatric training is not included at any level of audiology education.

Between May 2007 and May 2009, only two diagnostic centers were available in the state. Approximately 70 audiologists are licensed to practice in New Hampshire each year, and fewer than twelve of them have the skills and education needed to test infants and young children. Fortunately, two audiologists relocated to the state. In May 2009, one audiologist reopened a diagnostic center in an otolaryngology practice. The other new audiologist established a new diagnostic center in the Audiology Department of a large urban medical center. Both facilities are located in the more populous southern region of New Hampshire. Site visits and numerous communications lead to the start-up of these new centers. (A map of the diagnostic centers and birth facilities is in Attachment 6.)

The EHDI Program is committed to reducing loss to follow-up of infants who did not pass their final hearing screening and have not obtained diagnostic hearing testing. Currently, four audiologic diagnostic centers provide testing in New Hampshire. An additional diagnostic center with two audiologists is expected to open in Manchester, the largest city in the state, in 2014. The EHDI Consulting Audiologist, Consulting Family Advocate and Program Coordinator meet several times a year with the audiologists from the Pediatric Audiology Diagnostic Centers.

Additional visits are made to audiologists developing new centers, centers with new personnel, for quality improvement activities or upon request.

Some families choose out of state diagnostic testing sites because of their proximity or personal choice. To ensure that infants are not lost to follow up, the NH EHDI Program Coordinator spoke directly with audiologists who test infants in Massachusetts and Maine. These out-of-state audiologists were asked to obtain parental permission and report to the NH EHDI Program the diagnostic results within two weeks anytime they test infants who reside in NH. The Program Coordinator also contacts any instate or out of state audiologist for results if a report has not been received two weeks after the appointment date. If a family or provider reports that an infant from NH was tested out-of-state, the Program Coordinator also requests those results. Since audiologists already send reports to the newborn hearing screening program in their own state, they usually do not need to be reminded to send test results to the NH EHDI Program Coordinator.

Audiologists report difficulty in recruiting additional audiologists or obtaining professional continuing education in New Hampshire. There are no doctoral programs for audiologists in New Hampshire and only four doctoral programs in other New England states. Arranging and attending continuing education programs is expensive; requires travel by both speakers and learners; and is only available at one time in a specific place. The proliferation of on-line courses and programs for formal or continuing education has demonstrated that on-line teaching is successful. The EHDI Program staff would like to facilitate the use of on-line programming and either create or sponsor continuing education so that pediatric audiologists can learn without leaving New Hampshire.

### **Family-Centered Early Supports and Services**

All New Hampshire pediatric audiologists who test infants refer families of deaf and hard of hearing infants to an early intervention program. In New Hampshire, a family with a deaf or hard of hearing child is usually eligible for early intervention services. These programs, called Family-Centered Early Supports and Services (FCESS), are available by geographic regions of the state. There is also a statewide early intervention program, the Multi-Sensory Intervention through Consultation and Education (MICE), for infants and toddlers with vision or hearing loss.

The MICE Program provides services to over 200 infants and their families per year in all parts of New Hampshire. Services are provided at the child's home or childcare and frequency of services vary depending on need and severity of the vision or hearing loss. This service is funded through a grant from Health and Human Services-Division of Developmental Services FCESS Program. MICE works extensively with local Early Supports and Services agencies to provide the expertise regarding the needs of infants and toddlers with vision or hearing loss. The NH EHDI Follow-up Coordinator (family advocate) is a staff member of the NH Coalition of Citizens with Disabilities, aka, the Parent Information Center, the parent organization of MICE. This co-location is strategic and allows NH DHHS to leverage partnerships and promotes maximum opportunity for families to be connected to the appropriate services in a timely way.

The EHDI program staff has also met with staff from home visiting programs funded by the NH Division of Public Health Services and the NH Head Start/Early Head Start programs, to add another avenue for connecting families with the early intervention programs.

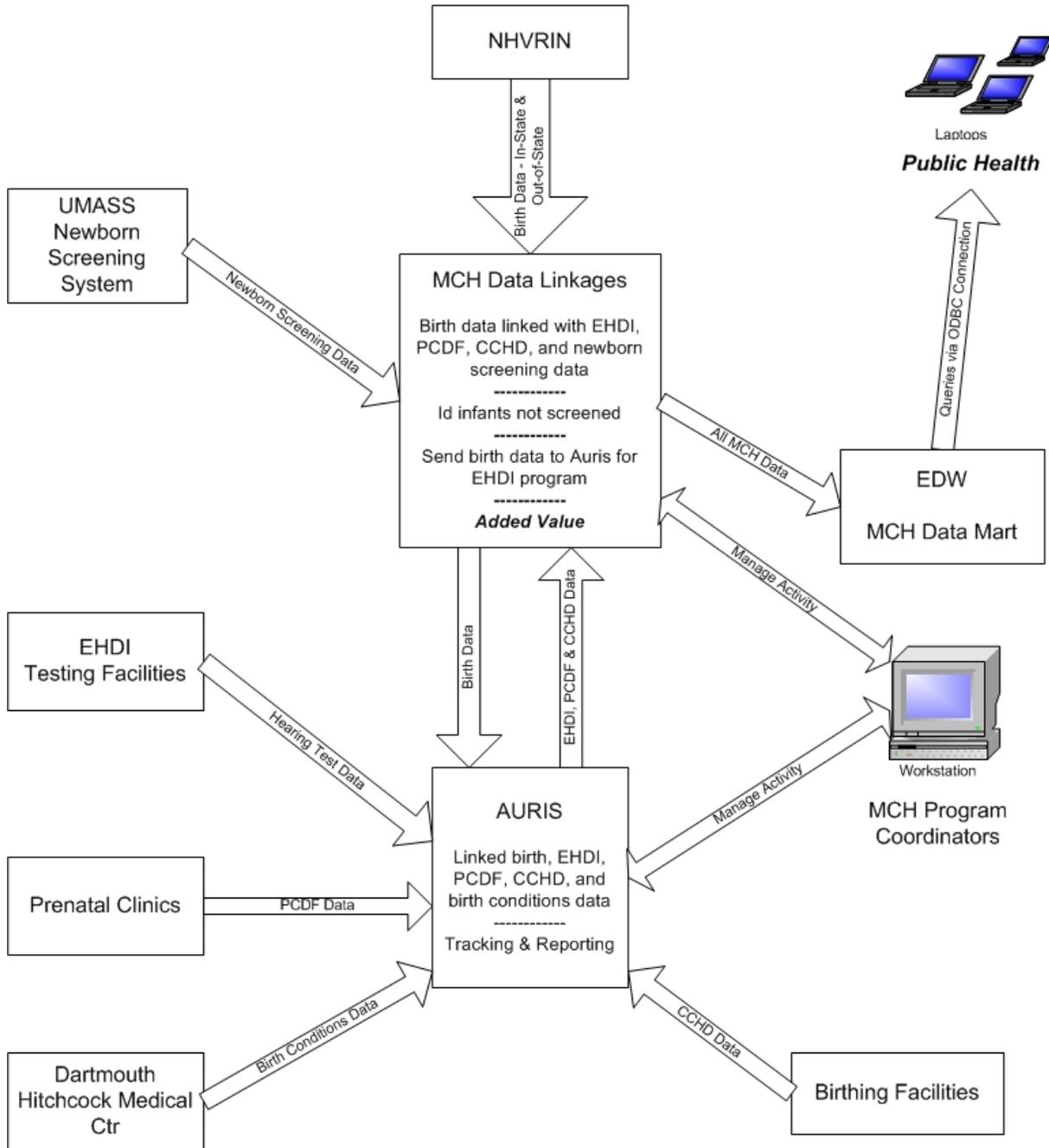
### **Data and Surveillance**

Obtaining and linking vital records and other infant hearing screening-related data is necessary for meeting national and state performance measures and for conducting quality improvement activities with providers throughout New Hampshire. The New Hampshire EHDI Program has maintained a vendor agreement with Welligent for the Auris system since 2004. AURIS links New Hampshire Vital Records Birth data. EHDI Program full time Program Coordinator, half time Nurse Specialist, part-time Consulting Audiologist and part-time Follow-up Coordinator (family advocate), all have secure access to this system to ensure timely follow with families and providers.

The AURIS system is embedded within New Hampshire's integrated system of linked MCH data sets that assist in fulfilling several critical public health functions: identification of infants not screened for hearing and metabolic disorders, and the identification of disparities among the prenatal population receiving MCHS-funded community-based services among other MCH populations in the state, and the evaluation of the effectiveness and accessibility of health services provided by the MCHS.

The following Figure illustrates the NH MCH Data Linkages. New Hampshire Vital Records, including in-state births and deaths are received daily and are linked with the NH EHDI data uploaded from New Hampshire hospitals or now freestanding birth hospitals through a web based system AURIS system. The Figure also illustrates that EHDI is integrated among the wide variety of the many other MCH data sets that use Vital Records for surveillance and quality assurance.

## NH MCH Data Linkages



The New Hampshire Birth Conditions Program (NH BCP), a population-based, surveillance program and collaborative effort between [Geisel School of Medicine at Dartmouth](#) and the NH Department of Health and Human Services, also uses the AURIS system creating a synergy between EHDI and the BCP. About 1 in every 33 babies is affected by structural or chromosomal anomalies. The BCP serves as a primary resource for information on congenital birth conditions in New Hampshire, and provides surveillance through AURIS and active case finding, research, and health care service delivery policy/ prevention recommendations. Considering that

hearing loss is the most common developmental disorder identifiable at birth, it is imperative that EHDI and BCP continue coordinated strategic planning and other surveillance efforts. Toward this end, the EHDI Program Coordinator continues to participate as a member of the NH BCP Advisory Council.

### **Feedback from Families**

In 2011, New Hampshire EHDI partnered with New Hampshire Family Voices and the MICE Program to administer an electronic survey to gather feedback from parents with newborns to children age 6 enrolled in the Multi-Sensory Intervention through Consultation and Education (MICE) Program and the Family Centered Early Supports and Services (FCESS) Program, to gather information about the newborn hearing screening and diagnostic process. Family Voices estimates they received feedback from 44% of families with young children identified with moderate to severe hearing loss, referred to a testing center and/or the NH Family Centered Early Supports and Services (FCESS) services.

As part of the survey, parents reported the time between receiving a diagnosis and their evaluation through FCESS. Most respondents (64.5%) reported between 1-3 months. Two families (6.5%) said less than a month and 12.9% said between 4-6 months. Five families (16.1%) reported more than six months. When matched with written comments these five families children spent significant time in the NICU/PICU or in the hospital their first year of life. One parent described that their child began ESS at four months of age due to low muscle tone and the hearing loss became more evident as speech and language skills emerged.

Parents also described that when a child is diagnosed with a hearing loss, they want to speak face to face with caring professionals and with other knowledgeable parents of deaf and hard of hearing children. Other communication strategies such as Facebook or social media are dependent may be more correlated with age.

Specific feedback from one parent:

*“I found all the information we received very informative. However, the volume of information we received all at once right after we found out that our son was deaf was very overwhelming and I found some of the written information especially terrifying because it was usually much more clinical and statistical”*

### **Summary of Needs**

New Hampshire is fortunate in that it often compares favorably to other states when considering birth outcomes. New Hampshire hospitals with birth facilities voluntarily established newborn hearing screening programs without legislation. Their staff members have actively participated in quality improvement efforts to improve screening and re-screening rates. For the past three years, over 97% of all infants born in New Hampshire had a newborn hearing screening. Four diagnostic centers are available to test any infants who do not pass their final hearing screening. The NH EHDI Program staff has worked to ensure that everyone has access to the services of a Follow-up Coordinator (family advocate) to guide them through the referral process. A Family Resource Book and other EHDI Program materials were developed for the families of all deaf or hard of hearing infants and young children. Training for new screeners is provided when requested.

New Hampshire is a small state with a small population, so small changes such as offering newborn hearing screening to all infants born at home or in freestanding birth centers, will have an immediate positive effect on the newborn hearing screening rate. The EHDI staff will also encourage the use of strategies that are known to reduce loss-to-follow-up after hospital discharge: making follow-up appointments at hospital discharge, using telephone reminders for follow-up appointments, and scheduling two diagnostic appointments two weeks apart at hospital discharge. To obtain timely follow up reports from providers, the EHDI's American Academy of Pediatrics Champion for New Hampshire has drafted a letter to colleagues requesting that they provide information regarding the baby's appointment after they've failed their newborn screening test.

The EHDI Program needs to ensure timely access to appropriate services to identify and support all infants who are deaf or hard of hearing. The in-depth analysis of program activities should identify practices that lead to parents scheduling and attending appointments for timely diagnostic testing. Activities that are found to encourage prompt entry into early intervention services will be sustained and any negative influences will be changed. Supporting and increasing activities that encourage appropriate follow-up will enhance the lives of infants who are deaf or hard of hearing. In addition, the Auris tracking system needs improvement in the programming of the system to generate timely and accurate reports.

Because hearing loss can occur at any age and could hinder learning, it is important that passive hearing assessment methods be shared with others who work with young children. The EHDI Program staff plans to share their knowledge of hearing screening with other groups who work with infants, toddlers and their families. This has started with the Head Start and the Affordable Care Act (ACA) Maternal Infant Early Childhood Home Visiting (MIECHV) programs, and has the potential to involve others in the future.

Although, the NH EHDI Program does not currently have an "official" advisory committee, it has begun the process of revitalizing a Quality Improvement Committee, with new stakeholders and former members of the Advisory Committee. The EHDI Coordinator continues to serve on the Legislative Committee on Deafness and Hearing Loss. The consulting audiologist attends audiology and vocational services meetings with former committee members. The program distributes updated materials and newsletters to a robust list of hearing and early childhood advocates. With the new grant, a team of stakeholders will be brought together which will include some hospital personnel, the AAP EHDI champion and the co-directors of NH Family Voices. This will serve as a mechanism to guide the program in its quality improvement work.

### **III. Methodology**

The NH EHDI Program proposes a methodology that utilizes quality improvement practices to ensure that New Hampshire continues to make significant progress in improving the national goals of completing hearing screening by 1 month of age, completing diagnostic testing by 3 months of age, and enrolling in early intervention by 6 months of age. These steps will ultimately lead to providing young children with a healthy start, strong family support, and positive early learning experiences

The NH EHDI team consists of the full time Program Coordinator, the half time Program Specialist, both of whom are employees of the NH Division of Public Health Services; a part time Consulting Audiologist and a part time Follow-up Coordinator, both of whom are

consultants to the program through vendor agreements. (See Attachment 2, Job Descriptions, Attachment 3 Biographical Sketches, and Attachment 5 Project Organizational Chart).

The contract with the Follow-up Coordinator is known as EARS (Education, Advocacy, Resources and Support for Families with Infants and Children who have a Suspected or Confirmed Hearing Loss). The Follow-up Coordinator is from the NH Coalition of Citizens with Disabilities. This organization is also known as MICE (Multi-Sensory Intervention through Consultation and Education). This position is critical in meeting family needs and providing the follow up and warm handoff that will ensure that infants with positive screens receive appropriate diagnostic testing and that those with confirmed hearing loss receive appropriate services in the setting most convenient for the family. This family advocate is specifically trained to meet the needs of the growing diversity of the state as well as the specific needs of the Deaf community.

All members of the EHDI team participate in staff training and professional development activities. The Program Coordinator and the Consulting Audiologist routinely attend the annual EHDI national meeting. The EHDI team updates key stakeholders with program newsletters, emails, meetings, and conference calls as indicated.

The Program AIMS are reflected in the goals, objectives and activities of the workplan. These strategies mirror the national goals of completing screening by one month of age, completing diagnostic testing by 3 months of age, and enrollment in early intervention by 6 months of age.

The EHDI team participated in a NICHQ Collaborative in 2010 & 2011. The EHDI team will continue using the Model for Improvement developed by Associates in Process Improvement to improve outcomes for the all newborn hearing screening activities in New Hampshire. The Quality Improvement strategies are #1: scripting the message to the parents, #2: using FAX-back forms between multiple providers, #3: ascertaining the name of the infant's primary care provider, #4: identifying a second point of contact for the family, #5: making rescreening or diagnostic testing appointments for the infant at hospital discharge, #6: telephone reminders for appointments, #7: scheduling two audiology appointments two weeks apart at hospital discharge, #8: streamlining the early intervention referral process and obtaining a consent for release of information, and #9: improving data tracking.

The EHDI team is currently revitalizing and recruiting new members for the Quality Improvement (QI) Committee that had been mobilized for the 2010/11 NICHQ Collaborative.. This committee will replace the former EHDI Advisory Committee which was officially "sunsetting" by legislative authority. The members of this new QI Committee will include, at a minimum, the EHDI team, a parent of a child with a hearing loss, a representative from the state's early intervention program, and an epidemiologist/statistician. Others that will be invited include a Co-Director of NH Family Voices, the American Academy of Pediatrics' NH Chapter Champion, and a representative from Home Visiting/Early Head Start, the MCH Title V Quality Assurance Nurse Consultant, and a selection of newborn hearing screening managers from birthing facilities.

Meetings of the QI Committee will be held three times yearly: May, September, and January, with the first meeting will scheduled for May 2014. The first meeting will focus on crafting an AIM statement, orienting the committee members to Plan Do Study Act (PDSA) cycles, and planning an evaluation project related to increasing the rate of scheduling

appointments to audiologic diagnostic centers prior to discharge home. Future meetings will identify change strategies, work with birth facilities to conduct PDSA cycles, analyze results to determine if the change results in improvement, discuss challenges, and expand and test successful strategies on a larger scale, to other birth facilities. It is anticipated that smaller workgroups will meet more frequently to discuss small tests of change and to prepare for larger quarterly meetings.

The first evaluation project will focus on activities that worked in the high performing facilities, then plan and encourage low performing agencies to conduct small tests of change that will increase appointment rates. The second evaluation project will focus on activities to improve timely enrollment in the state's early intervention program.

*Quality Improvement Strategy #1: scripting the message to the parents*

A scripted message for providing newborn hearing screening results to parents was developed by members of the previous Q I Committee in 2007. The message continues to be promoted and used by those reporting results to parents. Trainings for new birth facility staff include use of the parent messaging. The message is delivered by a variety of birth facility staff members including professional and ancillary staff. Evaluation and use of the scripted message will be assessed in Grant Year 2 by the QI Committee.

*Quality Improvement Strategy #2: using FAX-back forms between multiple providers*

Audiologists who test infants and young children previously reported that making phone referrals to early intervention programs was time-consuming and often led to multiple voice mail messages. The Consulting Audiologist and the Follow-up Coordinator developed, tested and refined a referral form in the fall of 2013 for audiologists to complete and fax to the regional early intervention agency. The next step will be to ask one audiologist to pilot use of the form using a PDSA cycle as outlined in Goal 3, Objective 1 of the workplan.

*Quality Improvement Strategy #3: ascertaining the name of the infant's primary care provider*

The name of the infant's health care provider after discharge is supposed to be entered into the AURIS tracking system. When the Follow-up Coordinator is unable to reach the family of an infant who needs diagnostic testing, she asks either the EHDI Program Coordinator or the EHDI Program Nurse Specialist, to follow-up with the primary care provider. This method has been successful and will continue. This is a critical step that reduces loss to follow up and ensures continuity of care prior to the infant reaching the three month milestone.

*Quality Improvement Strategy #4: identifying a second point of contact for the family*

The AURIS tracking system has a field for a second point of contact; however, its use is not required, and it is often not utilized. Data will be assessed in Year 2 to determine if an evaluation activity is needed to improve coordination between the Follow-up Coordinator and the parent, which could result in increased rate of diagnostic evaluation.

*Quality Improvement Strategy #5: making rescreening or diagnostic testing appointments for the infant at hospital discharge*

A survey of the twenty birth hospitals was conducted in the fall of 2012 to determine if staff was scheduling appointments for diagnostic testing by phone or fax prior to discharge, or were having the parent or primary care provider schedule the appointment after discharge.

Preliminary data is leading to showing higher rates of diagnostic evaluation when the appointment is made prior to discharge. Year 1 of this grant will include an evaluation activity about testing rates in relation to method of referral as described in Goal 2, Objective 1 of the workplan.

*Quality Improvement Strategy #6: telephone reminders for appointments*

Currently, there is no New Hampshire data on whether telephone reminders are made to parents by audiologic diagnostic centers. In Year 2 or 3 of this grant, the EHDI Program will discuss with the QI Committee the need to conduct a survey and develop an evaluation project related to whether reminder calls are related to higher rates of diagnostic testing by 3 months of age.

*Quality Improvement Strategy #7: scheduling two audiological diagnostic appointments two weeks apart at hospital discharge*

Currently, audiologic testing facilities will only schedule appointments one at a time. Further data analysis is needed to determine if this is an issue that impacts diagnostic testing completion rates by 3 months of age.

*Quality Improvement Strategy #8: streamlining the early intervention referral process and obtaining consent for release of information*

Currently, the early intervention program obtains parent consent to report the date of early intervention enrollment. Data reports indicate that some of the dates of enrollment are missing; however, it is not apparent whether the problem is due to data not being entered or consent not being obtained. Collaboratively, the EHDI Program, the state early intervention program, and the Multisensory Intervention through Consultation and Education (MICE) Program developed a 3-way parent consent form in 2011 to allow reporting of the early intervention enrollment date to the EHDI Program. Streamlining the process with the new 3-way consent form appears to have increased reporting.

*Quality Improvement Strategy #9: improving data tracking (AURIS)*

The EHDI-IS AURIS data tracking system was initiated in 2004 through a contract with Welligent. Data fields were changed several years ago to reflect the revised data definitions from the Centers for Disease Control and Prevention. This created multiple challenges with extracting data and generating accurate reports. Recent data indicate that many of the problems have resolved. Evaluation activities in Year 1 of the new grant cycle include validating two AURIS reports as mentioned in Goal 1, Objective 1.2; Goal 2, Objective 2.2; and Goal 3, Objective 3.2.

*Sustainability*

The NH EHDI Program was established thirteen years ago. The program does not provide any funding to hospital-based newborn hearing screening programs or pediatric audiology diagnostic centers. The program provides consultation, education and monitoring of newborn hearing screening activities. The EHDI team has a fulltime EHDI program coordinator, a halftime program specialist, and maintains a part-time consulting audiologist and a part-time follow-up coordinator/family advocate through vendor agreements. The Centers for Disease Control and Prevention funding for EHDI activities provide significant support for data support, infrastructure and linkages. Leadership and oversight are provided by the MCH administrator who is funded by Title V. The EHDI team oversees all newborn hearing screening activities at

twenty hospitals with birth units, four freestanding birth facilities operated by certified lay midwives and four pediatric audiology diagnostic centers. If grant funding is discontinued, Title V funding or other resources within the Department of Health and Human Services may be used to support minimal quality assurance and surveillance activities of the EHDI Program.

#### **IV. Workplan**

See Attachment 1: NH EHDI Program Workplan

#### **V. Resolution of Challenges**

New Hampshire is a small state based on population and geographic area. Its residents have historically shared good health outcomes. Newborn hearing screening is not legislatively mandated yet over 97% of newborns received newborn hearing screening in 2012. Part of this success can be attributed to the EHDI Program staff and consultants having developed close working relationships with birth facility personnel and audiologists who test infants throughout New Hampshire. The NH EHDI Program does experience challenges including limited resources.

The majority of women deliver infants in one of twenty birthing hospitals in the state. Midwives attend approximately 200 births per year, almost half of which are at home, and the other half are at freestanding birth centers that offer newborn hearing screening. The NH EHDI program provided free screening equipment to each of the four facilities to overcome financial barriers. The EHDI Program Coordinator and Consulting Audiologist have been collaborating with the midwife at the fourth free standing birth facility to promote newborn hearing screening and offer education and support as needed. To date, the midwife has not made a final decision if she will offer newborn hearing screening and infants born at this facility are not routinely offered newborn hearing screening at another site. The hearing screening equipment will be returned to the EHDI Program by the spring of 2014 or sooner if she decides not to screen or if no decision has been reached. This equipment will be redistributed to another midwife who does home births.

The EHDI Program does not offer any financial support to agencies that provide newborn hearing screening, audiology diagnostic evaluation, or early intervention. Hospitals, birth facilities and audiology diagnostic centers must use their own resources to enter data into the Auris Tracking System. One of the activities described in the workplan under goal #2 includes getting low performing birth facilities to change their method of referral. Several different referral methods, some of which have been more successful than others, have been used. The EHDI Program will be working to encourage hospitals and birth facilities to use one of the more successful methods: faxing referrals to the diagnostic center or scheduling appointments directly with the diagnostic center and giving the parents the appointment card before the baby is discharged home. Trying to get the hospitals to change their current referral process may pose a challenge as the time to call and make the appointment directly with the diagnostic center may not occur when hospital staffing has the capacity to do so, and at the same time, when the diagnostic center is open. Training on using this fax referral process will be needed for both hospitals needing to change to this method, and the diagnostic centers receiving the faxes. Additionally, the infant's primary care provider may prefer to retain control of this step of the process, and make the referral from their office. The EDHI Program will be working on these challenges in the upcoming grant cycle.

A consistent challenge has been the ability to generate accurate reports from the Auris system. Changes were made to some of the data fields, which caused errors in several of the reports. EHDI staff has worked closely with the contractor to correct these problems and are confident that these reports now reflect accurate data. All three goals in the workplan address validating individual client data on a semi-annual or quarterly basis.

Audiologists at four diagnostic centers have provided diagnostic testing for the past three years. However, there has never been a testing center in Manchester, NH, the state's largest city. This is about to change. Elliot Hospital, the largest birth facility in the state, is developing a diagnostic testing facility in the hospital. The audiologists have been hired and expect to start set up the diagnostic testing equipment in January 2014. The Consulting Audiologist is working directly with them to assure that the facility is fully operational before the audiologists begin testing infants who fail their final screening. Attachment 6 is a map of New Hampshire, which shows the location of the pediatric audiology diagnostic centers.

In the past the NH EHDI Program has had an advisory committee made of internal and external stakeholders. This committee was sunsetted by legislative authority. In 2014, the NH EHDI Program will form a new QI Committee as described in the Methodology section and in the workplan. Historically, it has been challenging engaging an external stakeholder who is a parent of a deaf or hearing-impaired child to participate on our committee. The NH EHDI Program will work with staff from MICE and NH Family Voices to overcome this barrier as it forms the new committee.

## **VI. Evaluation and Technical Support Capacity**

The EHDI Program has resources and capabilities to continue to support parents, birthing facilities, diagnostic centers, and early intervention programs by providing audiology consultation services, and educational resources for parents and professionals. These include a resource book for parents, links to local, state, and national resources available from the NH DHHS website, and social media messages through both NH DHHS tweets and press releases in observation of Better Hearing Month (May). The program also provides hearing screening equipment to freestanding birth facilities and assistance with policy development to birth facilities. The EDHI-IS Auris tracking system captures data elements on all infants born in New Hampshire. These data fields are critical so staff can monitor individual newborn hearing screening results and track infants who need follow-up. Auris reports allow EHDI staff and consultants to analyze and track data to measure change strategies. Staff monitors individual patient data fields to ensure that all infants born in New Hampshire are captured in Auris (import birth registry data). EHDI Program staff monitor data for completeness and accuracy of information. Staff utilize the data and reports to drive evaluation activities and monitor program performance related to newborn hearing screening by 1 month of age, diagnostic evaluation by 3 months of age, and enrollment in early intervention by 6 months of age.

Patricia Tilley, MS Ed will continue to serve as project director. Ms. Tilley was promoted from MCH Section Administrator to Bureau Chief, but continues to oversee MCH in the absence of a replacement. She has over 15 years of experience working with families and health and social service programs. Audrey Knight, RN, MSN is the Child Health Nurse Consultant for MCH, with over 20 years of experience in her role. Ms. Knight will provide expertise regarding access to systems of care for children, and supervise Ruth Fox, RN, MS, EHDI Coordinator and Holly Wentworth, RN, EHDI Program staff. Ms. Fox will continue to manage the day-to-day

operation of the EHDI Program by monitoring hospital programs and providing feedback to hospital staff about screening rates, rescreen rates, missed infants and timeliness of referrals. Ms. Wentworth will continue to oversee the data entry aspects of the EHDI Program. Mary Jane Sullivan, Consulting Audiologist, will continue to work in the program, especially with the audiologists at diagnostic centers. Dawn Zimmerman, Follow-up Coordinator, will continue to support families with infants who refer on their final hearing screening and assist them in obtaining diagnostic testing for their infants. Please see Attachment 2: Job Descriptions for Key Personnel and Attachment 3: Biographical Sketches of Key Personnel for additional details.

Programs throughout the Division of Public Health Services have used performance measures for contracts with agencies throughout New Hampshire for many years. Since the implementation of the Auris tracking system in 2004, the EHDI staff has used performance measures to evaluate the hospital newborn hearing screening programs and help program managers to identify areas for improvement. With the help of the MCH Quality Assurance Nurse Consultant, the EHDI Program staff has established performance measures that address the quality assurance activities in all aspects of the newborn hearing screening process.

Historically, New Hampshire has high newborn hearing screening rates by one month of age. The NH EHDI Program has specific screening protocols that are used in New Hampshire birth facilities and are specific for each type of screening method. Otoacoustic Emissions (OAE) screeners, Auditory Brain Response (ABR) screeners and combination (OAE and ABR) screeners are used in New Hampshire. Two hospitals and three freestanding birth centers use OAE only equipment to screen infants born in their facilities. Combination OAE and ABR equipment is used for hearing screening in 4 hospitals. The majority of hospitals in New Hampshire (70% or 14 of 20 birthing hospitals) use ABR only equipment.

Hospital staff members were instructed on the use of the Auris tracking system and began reporting hearing screening results through Auris in January 2004. As shown in Table 4, the percent of newborns who completed newborn hearing screenings have remained about the same for the past three years.

Table 4: Percent Completed Newborn Hearing Screens by Year

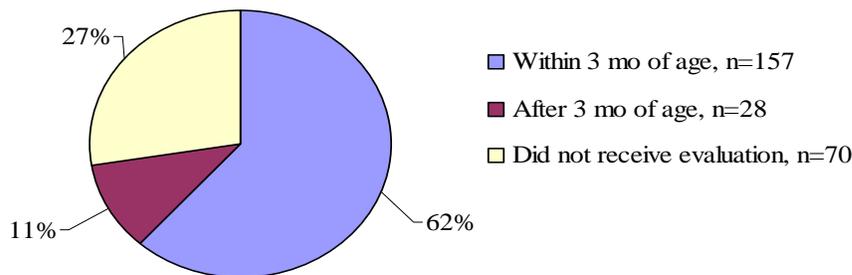
Year	Number of facilities	Number of completed newborn hearing screenings	Number of births	Percent of completed newborn hearing screenings
2010	21	12,717	13,032	97.5%
2011	21	12,733	13,080	97.3%
2012	20	12,249	12,578	97.4%

Evaluation activities will focus on EDHI information data report (EHDI-IS) accuracy. The evaluation question that New Hampshire will explore is: To what extent is the EDHI-IS “Hospital Performance Measure Report” accurate? Goal #1 in the workplan specifically addresses evaluation activities that will be used to answer this question and include quarterly validation of individual client data, collaborating with the EDHI-IS contractor to correct inaccuracies in the “Hospital Performance Measure Report” as needed, distributing an annual

agency-specific “Hospital Performance Measure Report” to each birth facility including the four free-standing birth facilities, and sharing de-identified data with stakeholders.

Two hundred fifty-five infants were referred for diagnostic evaluation in 2012. Outcomes are displayed in the chart below. One hundred fifty-seven (62%) of referred infants received a diagnostic evaluation by 3 months of age and twenty-eight (11%) were evaluated after three months of age. Seventy of the 255 referred infants (27%) did not receive a diagnostic evaluation in 2012. The Q I Committee will work towards improving this outcome during this 3-year grant period.

Infants Referred for Diagnostic Evaluation, 2012, N=255



According to a survey of perinatal nurse managers conducted in 2012, hospital newborn hearing screening programs refer infants who do not pass their final hearing screening are referred diagnostic evaluation in one of four ways: scheduling a diagnostic testing appointment via phone before the infant is discharged, faxing the referral information to the selected testing facility before discharge so that staff can contact the family and schedule an appointment, giving parents a current list of diagnostic testing facilities and instructing them to schedule an appointment, or contacting the infant’s provider with a request to assist the parent(s) in scheduling an appointment after discharge. In 2013, EHDI staff analyzed data related to completion of diagnostic evaluation by 3 months using the four different methods mentioned above. No definitive conclusions could be made regarding the timeliness of diagnostic evaluation based on referral method because many of the birthing facilities had been using their current referral method for less than 12 months and not all facilities implemented the referral method at the same time. Evaluation activities will focus on accuracy of the EDHI-IS report and referral methods. Two evaluation questions will be explored: To what extent is the “Timeliness of Diagnostic Testing Report” accurate?; and Does scheduling an appointment by birthing facility staff lead to higher rates of diagnostic evaluation by 3 months of age than scheduling an appointment by the primary care provider or parent after discharge? Goal #2 in the workplan specifically addresses evaluation activities that will be used to answer these two questions. Evaluation activities for the first evaluation question include quarterly validation of individual client data and collaborating with the EDHI-IS contractor to correct inaccuracies in the “Timeliness of Diagnostic Testing Report” as needed. Evaluation activities for the second evaluation question include surveying birth facility managers and midwives, analyzing EDHI

data, inviting birth facility managers to join the QI Committee, conducting PDSA cycles, and sharing findings with stakeholders.

The MCH QA Nurse Consultant is available to assist the EHDI Program staff when addressing the quality improvement strategies needed to further reduce the number of infants and families who are lost to follow-up following a failed hearing screening.

Of the 185 infants who received a diagnostic evaluation in 2012, 16 had documented hearing loss. Obtaining data on infants enrolled in early intervention by 6 months of age continues to be challenging as previously mentioned. Evaluation activities that increase the percent of infants who enroll in early intervention by 6 months of age will focus on referrals made by diagnostic center staff to early intervention programs. The evaluation question we will explore is: Does faxing a referral by diagnostic center staff lead to higher rates of early intervention enrollment by 6 months of age versus leaving phone messages at early intervention programs? Goal #3 in the workplan specifically addresses evaluation activities that will be used to answer this question and will include using fax referrals to early intervention programs, conducting PDSA cycles, monitoring data, and sharing findings with stakeholders.

The NH EDHI team is familiar with the PDSA cycle and has used this method with success. The Q I Committee is being assembled and members not familiar with PDSA will be trained. The goal of PDSA is to test changes on a small scale for a specific time period or a limited number of events. If the change is not successful, the plan will be revised and another change cycle will begin. PDSA cycles will be a routine part of the evaluation activities.

## **VII. Organizational Information**

The EHDI Program is housed within the New Hampshire Title V Program in the Maternal and Child Section (MCH) of the Bureau of Population Health and Community Services, Division of Public Health Services, Department of Health and Human Services (DPHS). The Mission of DPHS is to assure the health and well-being of communities and populations in the state by protecting and promoting the physical, mental and environmental health of its citizens, and by preventing disease, injury and disability. Its vision is to be a responsive, expert, leadership organization that promotes optimal health and well-being for all people in the state and protects them from illness and injury.

It is MCH's goal that every child in New Hampshire has the opportunity to grow up healthy. MCH has historically been devoted to administering health programs and services for women, infants and children. It supports a broad array of programs in order to improve the availability of and access to high quality preventive and primary health care for all children and to reproductive health care for all women and their partners regardless of their ability to pay. It is supported in part by Title V funds. Priorities are based on a yearly review of statewide need, which is reported on in MCH's annual Title V Grant Application to the federal government.

MCH is well positioned to continue newborn hearing screening activities in New Hampshire. Expertise within MCH includes nurses, health educators, early childhood experts, public health professionals, epidemiologists, and a program evaluation specialist. MCH staff work as a multi-disciplinary team and are available to provide assistance to EHDI staff as they assure that all newborns born in New Hampshire are offered hearing screening, and maintain systems for assuring appropriate diagnosis and follow up of identified infants.

There are several related programs within MCH that have a wealth of expertise in the screening and follow up of infants and children with health conditions. The Newborn Screening Program carries out a variety of activities including: mandated testing of all newborns statewide for various inherited conditions; tracking of test results; initiating follow up with primary care providers for confirmatory testing; and working to assure timely interventions for newborns who test positive. The NH Sudden Unexpected Infant Death (SUID) Project, funded by the Centers for Disease Control and Prevention, monitors and tracks data related to infants who die suddenly and unexpectedly, and works with a variety of health professionals on a state and local level to reduce risk factors, improve access to services, and change policies to prevent further deaths from occurring.

MCH has also played a vital role in the development of a birth conditions surveillance system for New Hampshire. This project, initiated within MCH as a neural tube defects registry in 2000, has grown into a comprehensive, active surveillance system to track major birth conditions. MCH has worked closely with [Geisel School of Medicine at Dartmouth](#), to develop the surveillance piece of the initiative, and has assisted with the integration with the WIC program to incorporate folic acid education, the Special Medical Services Unit to incorporate access to medical homes, and the Early Intervention Program to assure appropriate referral of children with birth conditions.

The EHDI Program can draw on the expertise and assistance of its Title V sister organization, the Special Medical Services Unit, New Hampshire's agency for Children with Special Health Care Needs. The Special Medical Services Unit has a long history of providing care coordination for children with chronic conditions. Staff from the Special Medical Services Unit is available to provide care coordination and financial assistance for income-eligible families, including families of children identified as deaf or hard of hearing. Housed, physically, within the Special Medical Services Unit, is NH Family Voices, which also works closely with the NH EHDI Program. One of the Co-Directors of NH Family Voices will be a member of the upcoming EHDI Program Quality Improvement Committee.

Completion of the NH Integrated MCH Information System is facilitating the use of data from all MCH programs to improve services for families of infants who are deaf or hard of hearing.

The entire EHDI Program staff and consultants have developed close working relationships with hospital newborn hearing screening personnel, and audiologists, especially those testing infants, throughout New Hampshire. The EHDI staff continues to assist the hospital newborn hearing screening managers to identify areas needing improvement and monitor the progress of each hospital program toward these goals.

As presented in the Needs Assessment portion of this proposal, New Hampshire does not have legislation requiring newborn hearing screening. On December 22, 2005, the New Hampshire Joint Legislative Committee on Administrative Rules adopted rules that require anyone conducting newborn hearing screenings or diagnostic hearing evaluations to report the results to the EHDI Program. The Rules also require that facilities allow periodic review of newborn hearing screening activities by EHDI staff for quality assurance purposes. It should be noted that despite the lack of a legislative mandate, all hospitals with birth facilities offer newborn hearing screening. In 2012, 97.4% of infants born at a New Hampshire hospital had a newborn hearing screening.

The EHDI Program has resources and capabilities to support the provision of culturally and linguistically competent and health literate services. EHDI program material is written for low literacy levels. The Department of Health and Human Services has an Office of Minority Health and Refugee Affairs, which provides information and services for interpretation, translation, deaf/hard of hearing and other communication access resources. This includes over the phone interpretation, a language bank web portal, low vision resources, and the ability to get written documents translated upon request. Although none have been needed to date for the EHDI Program, interpreter services are available for non-English speaking families, and access to a TTY line is available for hearing impaired parents. As was done for past EHDI Program Advisory Committee Meetings, for any meetings that might involve hearing impaired parents or agency representatives, such as at the planned Stakeholders QI meetings, the program is able to utilize the services of interpreters to sign through Northeast Deaf and Hard of Hearing Services.

The unique needs of target populations of the communities served by this grant are routinely assessed and improved. In addition to the annual review of demographics for the Title V MCH federal grant application, every five years, MCH is required to submit a Needs Assessment. Through the Needs Assessment, in addition to demographic data, public input is obtained from professionals, advocates and families to identify and rank needs and priorities.

Feedback was also obtained by a survey of parents with deaf or hard of hearing children in 2011 conducted by NH Family Voices for the EHDI Program. The survey looked at services used, services desired, and helpful sources of information. Results of the survey were valuable in assessing the current services and planning future activities and resources. The EHDI Program will continue to work to be sensitive to the needs and best serve its target population.

The EHDI Program staff has previous experience regarding executing and implementing QI projects with its participation in 2011 in the NICHQ Collaborative. Efforts focused on the message for hospital screening staff to give parents whether the child had passed or failed through doing small tests of change. The experience of going through this process will be of great value as it explores the evaluation questions identified in the grant workplan and carries out workplan activities such as conducting PDSA cycles, monitoring data and sharing findings with stake holders.

In summary, the New Hampshire EHDI Program has the organizational structure, capacity and experience to continue providing excellent services to all infants born in New Hampshire and their families. With the EHDI Program now in its fourteenth year, newborn hearing screening is offered in all New Hampshire hospitals with birth facilities and three freestanding birth facilities run by certified lay midwives. It is well positioned to move forward in utilizing its data to monitor and improve identification of hearing loss and referral to appropriate services for its youngest residents.