I. INTRODUCTION

The New Hampshire Early Hearing Detection and Intervention (NH EHDI) Program is pleased to submit this application for funding to reduce the loss to follow-up after failure to pass newborn hearing screening in New Hampshire. The EHDI Program is housed within the New Hampshire Title V program in the Maternal and Child Health Section (MCHS) of the Bureau of Community Health Services, Division of Public Health Services, Department of Health and Human Services (DHHS). The NH EHDI Program began its work in newborn hearing screening in 2000. Over the past seven years, the program has matured and is well suited to move forward to meet the challenge of reducing the number of infants lost to follow-up in New Hampshire.

In 2000, the program coordinator was hired; a contract established for a consulting audiologist; an Advisory Committee was formed; and a survey of New Hampshire hospitals with birth facilities was conducted. According to the survey, infants born at three community hospitals or receiving care in the intensive care nursery of a tertiary care facility were offered newborn hearing screening during the birth hospitalization. By October 2003, the remaining nineteen hospitals with birth facilities offered newborn hearing screening and the tertiary care facility initiated universal newborn hearing screening. These 23 hospitals continue to offer newborn hearing screening to infants born in their facilities.

In 2002, after an extensive investigation of options led by an information management consultant, the NH EHDI Program established a contract with Welligent to provide ongoing administration, management, hosting, support and maintenance of the Auris tracking system (Auris). Auris is a secure, authenticated, web-based application to manage and report on hearing screening, birth, diagnostic and follow-up information for maternal and child health data collected in New Hampshire. Early in 2004, newborn hearing screening program staff at hospitals with birth facilities and audiologists at Pediatric Audiology Diagnostic Centers were trained to enter data directly into the same record for an individual infant. Hospital users are only able to view the records for infants born at or transferred to their facility. All entries are immediately available to the EHDI program staff. The EHDI coordinator is the database administrator of the Auris tracking system. Auris accepts data transfers from hospital information systems or from most hearing screening equipment. Many reports are available in the tracking system, new reports can be added, or a custom report feature can be used to obtain additional information.

A 2001 survey of audiologists revealed that audiologists at one tertiary care facility and one audiologist in private practice offered diagnostic testing for infants. Several audiologists in private practice and in health care facilities were interested in testing infants and young children, but lacked either the knowledge or equipment needed to offer diagnostic services. The EHDI coordinator and consulting audiologist worked with the staff at National Center for Hearing Assessment and Management (NCHAM) to bring diagnostic training to New England with a three-part program: on-line activities and discussion with an experienced audiologist, classroom and hands-on practice under the direction of a national expert and practical experience in a clinical setting with a mentor. Audiologists from New Hampshire attended diagnostic testing training in 2002. The NH EHDI Program provided funding for equipment and audiologic training for staff at four diagnostic settings. Audiology practices that meet the Joint Committee on Infant Hearing requirements for testing infants are designated as Level I Pediatric Audiology Diagnostic Centers. In 2000, two centers were conducting infant testing. From 2003 through 2006, an average of six diagnostic centers conducted infant testing. Between May 2006 and October 2007, the number of centers in New Hampshire declined to two because of staff resignations and decisions to stop offering infant testing.

Providing technical expertise and valuable insight and guidance, the EHDI Advisory Committee is composed of parents and professionals involved in all phases of newborn hearing screening and services for infants and children with hearing loss. The committee members meet three times a year. The meetings are well attended and the discussions lively. In addition to EHDI program staff, the consulting audiologist, and the New Hampshire American Academy of Pediatrics Chapter Champion, an additional member of the advisory committee attended the 2006 national EHDI meeting. Members of the advisory committee actively developed and edited sections of a Family Resource Book that is now distributed to families with children who are deaf or hard of hearing.

In early 2007, the New Hampshire Department of Health and Human Services, Division of public Health Services released the *Family Resource Book for Children Who Are Deaf* or Hard of Hearing. This comprehensive resource is designed for families to use during their child's early life. The resource book contains sections that address topics related to hearing loss including: audiologic testing, hearing aids, learning to talk, communication choices, services for young children, transition to preschool educational programs, national organizations, New Hampshire organizations, other resources including websites, and a glossary.

To further ensure that the needs of families were adequately addressed, in April 2007, the EHDI Program entered into a contract with the Multi-Sensory Intervention through Consultation and Education (MICE) Program, a statewide program for children from birth to three years of age with sensory impairments, including hearing loss. The contract provides education, advocacy, resources and services (EARS) for families of infants referred for diagnostic testing or confirmed with a hearing loss. The family advocate has a publicized telephone number to receive calls directly from family members. She responds to all referrals from hospitals screening staff, primary care providers, EHDI staff or MICE program staff within three business days. The family advocate attempts to contact by letter or telephone the family of all infants who did not pass their newborn hearing screenings. It is anticipated that the family advocate services will lead to more infants receiving diagnostic testing and enrolling in early intervention services.

At this juncture, the NH EHDI program is ready to move forward to reduce the number of infants lost to follow-up after failure to pass newborn hearing screening.

II. NEEDS ASSESSMENT

New Hampshire consistently ranks among the top states in the nation for many indicators or predictors of child well-being. In 2004, New Hampshire ranked third best in births to mothers with less than 12 years education (9.5%), first in total births to teens (5.7%) and first in births to mothers receiving late or no prenatal care (1.1%).¹ Also in 2003, New Hampshire ranked best in the country for the percent of people living in poverty in the past 12 months (7.7%) and best in the country for children under 18 years of age living in poverty (8.3%).² New Hampshire ranks fourth nationally for completion of childhood immunizations, 86.8% of children two and under were covered in 2003.³

These data paint a picture of a state where children, for the most part, begin life with many advantages, are healthy, have access to health care and economic security, and are able to avoid many consequences associated with less favorable statistics. However, New Hampshire's percent of low birth weight (LBW) babies increased by 35% between 1996 and 2002, well above the 4% increase nationally.⁴ This increase in LBW inevitably increases the number of health, education and social support services needed by New Hampshire's families now and when these children enter school.

Critical to meeting the health and development needs of all children, is the establishment of a medical home. <u>The National Survey of Children's Health⁵</u>, at the website <u>www.nschdata.org</u>, reported the following for 2003, the most recent year available: 61% of New Hampshire children received care that met the medical home definition, 95.2% of New Hampshire children had health insurance at the time of the survey and 10.6% of New Hampshire children were currently uninsured or not insured for some period in the past year. Table 1 compares the New Hampshire statistics with national statistics for 2003.

Indicator	New Hampshire	Nationwide			
Medical Home	61.0%	46.1%			
Current Health Insurance	95.2%	91.2%			
Consistency of Insurance					
Coverage	10.6%	14.9%			
Child and Adolescent Health Measure Initiative (2005), National Survey of					
Children's Health, Data Resource Center on Child and Adolescent Health website.					
Retrieved 10/11/07 from www.nschdata.org					

 Table 1: 2003 Statistics on Children's Health Care

¹ The Right Start Online, The Annie E. Casey Foundation, Baltimore, MD, http://www.aecf.org

² US Census Bureau, American Community Survey, 2003

³ National Immunization Survey, 2004

⁴ Kids Count, 2004, <u>www.kidscount.org</u>

⁵Child and Adolescent Health Measure Initiative (2005), *National Survey of Children's Health*, Data Resource Center on Child and Adolescent Health website. Retrieved 10/11/07 from <u>www.nschdata.org</u>

The population in northern New England is changing. New Hampshire, in particular, is experiencing challenges and opportunities associated with a diversifying population. With an 11% increase in population from 1990 to 2000, New Hampshire has seen a 23% population increase in urban areas and a 4% decrease in rural areas.⁶ Slowly, but significantly, the population is becoming more urban and more ethnically diverse. While 96% of New Hampshire children are white, the nonwhite population is expected to grow significantly in the coming years. Projections indicate that populations of Black and Hispanic children each have grown by 21%, and populations of Asian and Pacific Islander children have grown by 30%, between the years of 2000 and 2005.⁷ Since 1990, there has been a 22% increase in the number of residents with limited English proficiency.

The NH EHDI Program recognizes that newborn hearing screening programs and audiologic diagnostic centers are working to meet the needs of a diverse population. Hospitals and other health care organizations are improving access to care and improve the quality of services provided to all individual cared for at their facilities. Several New Hampshire organizations provide translation services and interpreters for clients who use other languages, including American Sign Language. For instance, a Spanish interpreter was provided for a preparatory home visit by the family advocate and an audiologic diagnostic testing appointment for a newborn who failed his hearing screening.

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. Yet, there are measures that can be taken to minimize poor outcomes. While proportionally fewer children in New Hampshire face significant risks compared to other parts of the country, there are still geographic, racial, ethnic and economic disparities that cannot be ignored.

DEMOGRAPHICS

An estimated 1.3 million people live in New Hampshire and approximately 14,000 births occur each year. In both 2005 and 2006, the mothers of 85% of the infants born in New Hampshire had completed high school. Private insurances paid for 70% of the births in 2005 and 68% in 2006. Medicaid paid for 26% of the births in 2005 and 28% in 2006. During both years, about 2.4% of births were self-pay and approximately 1.5% did not list any payor source. **Table 2** displays the characteristics of newborns born in New Hampshire in 2005 and 2006. Data from previous years is not available in the same format due to changes to the categories of information collected.

⁶ Kids Count, 2003, <u>www.kidscount.org</u>

⁷ Kids Count 1999, as cited in Kids Count New Hampshire 2003, <u>www.kidscount.org</u>

13,968 6,767 7,201 13,799 15 124 16 14 12,649 156 500 19 461 8 113	14,070 6,901 7,169 13,897 49 94 17 13 12,708 186 556 17 436 8
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19 461 8	17 436 8
461 8	436 8
8	8
-	
113	
115	101
562	614
165	160
1,313	1,251
3,234	3,334
2,378	2,588
1,294	1,291
3,468	3,323
1,325	1,328
327	285
464	510
3,658	3,925
27	44
179	159
63	37
9,465	9,359
339	339
237	207
	165 1,313 3,234 2,378 1,294 3,468 1,325 327 464 3,658 27 179 63 9,465 339

Table 2: Births Occurring in New Hampshire in 2005 and 2006

HOSPITAL NEWBORN HEARING SCREENING

There are 23 birthing hospitals in New Hampshire. Each New Hampshire hospital with birth facilities has purchased their own newborn hearing screening equipment. Of the 23 hospitals, three hospitals started offering hearing screening between 1996 and 1999; seven hospitals started in 2000; three hospitals started in 2001; five hospitals started in 2002; and five hospitals started in 2003.

In 2006, 97% percent of newborns were screened for hearing loss. The majority of New Hampshire hospitals had similar rates. Managers at the five hospitals that were identified as screening less than 95% of infants born at their hospital were asked to develop and implement a plan to improve their screening rates in June 2007. Preliminary data for the first three quarters of 2007 show that all New Hampshire hospitals, including those that previously had less than optimal outcomes, screened more than 95% of the infants born at their facility.

Infant deaths and transfers to out-of-state hospitals account for approximately 1% of the infants born in New Hampshire. It is probable that infants cared for in neighboring states are screened for hearing loss, but the results are not reported to the NH EHDI program. An agreement to share hearing screening results for residents of New Hampshire who had a newborn hearing screening in Massachusetts has been approved and signed by the Director of the New Hampshire Division of Public Health Services. New Hampshire DHHS, Division of Public Health Services is awaiting approval from the Massachusetts Department of Health. The draft agreement is described in Attachment A.

About 1% of the births in New Hampshire (169 infants in 2005 and 162 infants in 2006), occur at home or in freestanding birth centers, not hospitals. Most of these infants are not screened for hearing loss. Conversations with the midwives attending these births revealed that they recommend newborn hearing screening to their clients, but are unable to offer screening due to the cost of equipment. The EHDI Program plans to purchase a handheld OAE screener for use at a freestanding birth center. The midwives who use this OAE screener will be asked to offer newborn hearing screening to their own clients and the clients of other New Hampshire midwives.

PROTOCOLS AND RESCREENS

The NH EHDI program staff developed specific screening protocols for use with the OAE screeners, ABR screeners and combination (OAE and ABR) screeners. All of these screeners are currently used throughout the state. Staff at New Hampshire hospitals began reporting hearing screening results through the Auris tracking system in January 2004.

Table 3 shows the different protocols, the number of hospitals in each protocol group and the number of outliers, hospitals where too many rescreens were missed. On average, 6% of the births in New Hampshire occur in the three hospitals that use OAE/outpatient OAE. Approximately 27% of the births in NH occur in the four hospitals that use OAE/ABR prior to discharge. About 67% of the births in New Hampshire occur in the

sixteen hospitals that use ABR/ABR prior to discharge. The row "outliers" displays the number of hospitals in each group that missed more than 10% of re-screens during the given year.

	OAE/ Outpatient OAE Protocol	OAE/ABR prior to Discharge Protocol	ABR/ABR prior to Discharge Protocol	Total
Number of				
Hospitals	3	4	16	23
Percent of all				
NH Births	6%	27%	67%	100%
Number of				
Outliers in	1	2	13	16
2004				
Number of				
Outliers for	1	3	13	16
2005				
Outliers for				
2006	2	3	9	14
Source: New Hampshire Auris tracking system				
Analysis: New Hai	L	•••		

 Table 3: Hospital Re-screen Referrals

Most New Hampshire hospitals initiated newborn hearing screening programs within the past seven years. When asked by the EHDI program staff, most hospital managers or staff members assumed that they screened every infant born in their facility. The EHDI staff had no way to evaluate the performance of hospitals until hospitals began using the Auris tracking system in 2004. The EHDI coordinator and consulting audiologist have developed specific performance measures to evaluate hospital hearing screening programs. A report in the Auris tracking system calculates the hospital's performance for any desired period of time. The report includes: the percentage of infants screened for hearing loss prior to hospital discharge; the percentage of infants who did not pass their initial newborn hearing screening; the percentage of infants who had a re-screen; the percentage of infants who did not pass their final hearing screening; and the percentage of infants who did not pass a rescreen and were referred for follow-up.

In 2005, site visits were made and the 2004 performance measures were discussed with the managers. All hospital program managers are responsible for monitoring their program's performance. Managers of larger hospitals, those with a thousand or more births annually, are asked to review their program's performance quarterly.

VOLUNTARY PROGRESS

It is important to note that the tremendous progress New Hampshire hospitals have made during the past seven years in institutionalizing early hearing screening has occurred completely voluntarily: New Hampshire does not have legislation requiring 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. Time will be needed to work with program managers and staff to identify the actions needed to improve newborn hearing screening programs in all hospitals. Funding provided by this grant will support the staff activities needed to accomplish this and reduce the numbers of infants lost to follow-up in New Hampshire.

NH EHDI PERFORMANCE MEASURES

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 newborn hearing screening program. Staff at individual hospitals use the performance measures as a quality assurance activity. The EHDI staff uses the performance measures as an educational tool during site visits to hospital programs.

The performance measures for the past three years were used to calculate the numbers of infants lost to follow-up in New Hampshire between hospital and outpatient screening, between outpatient screening and audiologic diagnosis, and between audiologic diagnosis and entry into early intervention services. The number and percentage of children lost-to-follow-up are shown in **Table 3**.

Time Frame	2004	2005	2006	
1) Between hospital and outpatient	86/659	117/946	136/1034	
screening (rescreen)	13%	12%	13%	
2) Between outpatient screening	70/99	79/140	54/144	
(rescreen) and audiologic diagnosis	70%	56%	37%	
3) Between audiologic diagnosis and entry				
into Family-Centered Early Supports &	16/27	1/26	3/31	
Services	59%	4%	10%	
Source: New Hampshire Auris tracking system				
Analysis: New Hampshire MCHS				

Table 3: Infants Lost to Follow-Up

EARLY INTERVENTION AND FAMILY SUPPORT EFFORTS

The NH EHDI Program is the keystone between the process of newborn hearing screening in hospitals; the re-screening and diagnostic process for identified children; and ultimately in helping families access needed services. By parental request, the early intervention programs in New Hampshire are called Family-Centered Early Supports and Services (FCESS). In New Hampshire, all infants and young children identified with a hearing loss are eligible to enroll in FCESS. Specifically, the Multi-Sensory Intervention through Consultation and Education (MICE) Program, affiliated with FCESS, provides statewide program for children from birth to three years of age with sensory impairments, including hearing loss, in New Hampshire. Infants and young children are also enrolled in the FCESS Program serving the region where they live.

In an effort to compliment the services provided by Early Family Centered Early Supports and Services and provide appropriate referrals, in April 2007, the EHDI program facilitated a contract with the MICE Program to establish a new program called EARS: Education, Advocacy, Resources and Support for Families. A new position of family advocate was created. The role of the family advocate is to educate, advocate, resources and support families of infants with a known or suspected hearing loss. This contractual arrangement allows the family advocate to access the Auris tracking system to determine which infants did not pass their newborn hearing screening. She contacts the infants' families with a letter of introduction and follows up with a telephone call to verify that the family has an appointment at a Pediatric Audiology Diagnostic Center or assists them in scheduling an appointment. Newborn hearing screening staff at some New Hampshire hospitals schedule appointments for diagnostic testing. However, if the family is discharged in the evening or on the weekend, families are given the information to schedule the diagnostic testing appointment. At some hospitals, staff report the results to the child's health care provider or gives parents the contact information to schedule diagnostic testing appointments themselves.

Because the family advocate has access to screening information, EARS can be proactive in reaching out to families to ensure that any barriers are resolved in making diagnostic appointments. As part of their role, the family advocate discusses the preparation for an appointment, what diagnostic testing is like, and answers questions about testing or preparing their infant for diagnostic testing. It is anticipated that this will greatly reduce overall loss to follow up.

AUDIOLOGY DIAGNOSTIC SERVICES

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.

In 2007, 70 audiologists were licensed to practice in New Hampshire, although the total number of audiologists actively practicing in the state is not known. Of the audiologists practicing in New Hampshire, fewer than ten audiologists are able to test infants and

young children. The EHDI Program consulting audiologist is a practicing audiologist, part of the small group caring for infants and children. The EHDI Coordinator and consulting audiologist meet quarterly with staff at the Pediatric Audiology Diagnostic Centers. Audiologists from the centers and those seeing young children sometimes come together for discussions and trainings. During the past summer, meetings occurred at each individual diagnostic center.

Several years ago, the EHDI Program staff recruited audiologists to test infants referred by hospital newborn hearing screening programs and helped them obtain the needed equipment and training. However, some of these audiologists have since left New Hampshire and others have decided to no longer test infants. For example, one audiology practice (formerly a diagnostic center) was visited when the audiologist had completed training in infant testing. This facility was added to the list of Diagnostic Centers on September 1 2007, but was removed from the list on September 26, 2007 when the audiologist trained in infant diagnostics resigned. Conversations with audiologists and those seeking to hire audiologists, in New Hampshire. 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.

In July 2007, the EHDI consulting audiologist conducted an on-line survey of audiologists that specifically asked if they fitted hearing aids for infants or children and, if so, the ages of children served. Currently, there are three pediatric audiologists in the Audiology Department of a tertiary medical center and one audiologist who tests clients of all ages, including infants, in a private audiology practice. This means that as of November 2007, there are only two diagnostic centers operating in New Hampshire. A map is included as an attachment to further describe the locations of New Hampshire birth hospitals and the two remaining diagnostic centers.

On August 1, 2007, a notice was received that the Audiology Department of the tertiary medical center was limited to newborn hearing screening referrals from the northern part of New Hampshire. Some families living in southern New Hampshire, near the Massachusetts border, or coastal New Hampshire, near the Maine border, may obtain diagnostic testing in those states.

To ensure that these children are not lost to follow up, the NH EHDI Coordinator spoke at a September 2007 meeting of audiologists from diagnostic facilities in Massachusetts. She asked that they obtain parental permission and report test results to the NH EHDI Program anytime they test infants who reside in NH. This will document the date of diagnostic testing to verify that the infant was not lost to follow-up.

SUMMARY OF NEEDS

New Hampshire is fortunate in that it often compares favorably to other states when describing birth outcomes, poverty, and access to services. New Hampshire birth hospitals have voluntarily embraced newborn hearing screening and have actively participated in quality improvement efforts to improve screening and re-screening rates. The NH EHDI program has worked with families and advocates ensuring that other families have access to resources such as the Family Resource Book and a family advocate to guide them through the diagnostic process.

New Hampshire is a small state with a small population, so that even with modest financial resources, most families touched by hearing loss can access the EARS program and ultimately get enrolled in needed services. While the processes for reducing loss to follow up can be and will be enhanced with strategic attention, the most pressing current challenge is ensuring that with only two functioning audiology diagnostic centers serving infants, that all children receive the diagnosis in a timely way.

III. METHODOLOGY

The mission of the New Hampshire Department of Health and Human Services is to join communities and families in providing for citizens to achieve health and independence. As part of this mission, the newborn hearing screening activities of the EHDI Program are population-based services according to the pyramid of Core Public Health Services Delivered by MCH Agencies. According to this pyramid, the activities proposed in this grant application are Infrastructure Building Services.

The NH EHDI Program currently uses the Model for Improvement developed by <u>Associates in Process Improvement⁸</u> to improve outcomes for the hospital newborn hearing screening programs in New Hampshire. Attachment B provides an overview of the Plan-Do-Study Act Improvement Model. The EHDI Program will apply the model to make the changes needed to reduce the number of infants and families who are lost to follow-up.

The EHDI staff will focus on five of the effective strategies identified by the NICHQ learning collaborative and has added one similar strategy for scripting the message given to parents when an infant does not pass the rescreen. This additional script was included because the majority of infants born in New Hampshire receive both a hearing screening and a rescreen during the birth hospitalization. The parents are responsible for making and keeping the appointment for the diagnostic testing, which, in most instances, does not occur in the birth hospital. The EHDI staff felt that getting a second point of contact would be too difficult to implement at all 23 hospitals; making the re-screen appointment is not necessary because most newborns receive a re-screen prior to hospital discharge: making two audiology appointments at the diagnostic centers is not needed since additional appointments are scheduled without difficulty: and use of a fax back between specialists is not needed since they currently communicate well.

⁸From the IHI.org, A Resource from the Institute for Healthcare Improvement at http://www.ihi.org

With their seven years of experience, the EHDI coordinator and consulting audiologist are well known to the managers of newborn hearing screening programs at the 23 New Hampshire birthing hospitals.

To introduce the following strategies, the EHDI coordinator and consulting audiologist will convene an initial face-to-face meeting in Spring 2008 including hospital program managers and screening staff and pediatricians from the EHDI Advisory Committee, including the AAP Chapter Champion. From this group, it is anticipated that one or more working groups will be identified. The working groups will use the Plan-Do-Study-Act cycle to test and implement changes for strategies #1-4, which apply to hospital newborn hearing screening programs. It is expected that one of the hospitals represented on the working group will serve as the initial pilot site for each of the four strategies.

List of Quality Improvement Strategies

Strategy #1: Scripting the message to give the parents when an infant does not pass the initial screening

Strategy #2: Scripting the message to give parents when an infant does not pass the rescreen

Strategy #3: Using a fax form to alert infant's health care provider of screening results and the need for prompt follow-up

Strategy #4: Verifying the identity of the infant's health care provider before parents leave the hospital

Strategy #5: Making reminder calls before diagnostic testing appointments that include reasons why the appointment is important

Strategy #6: Obtaining consent for release of information at first contact with Family-Centered Early Supports and Services (FCESS), the title for Early Intervention programs in New Hampshire

Planning activities for Strategy #5 will begin with a meeting of the EHDI coordinator, consulting audiologist, family advocate and audiologists from the diagnostic centers. This will be added to the agenda of the planned spring meeting with the diagnostic center audiologists.

Planning activities for Strategy #6 will be discussed with the family advocate and Janet Halley, Director of the MICE Program, who supervises the family advocate. The MICE Program receives all referrals of children with hearing loss from the Pediatric Audiology Diagnostic Centers. This is the single entry point for early intervention services for infants and toddlers with hearing loss who live in New Hampshire. Our discussion will be added to the agenda of a monthly meeting with the EHDI coordinator and the consulting audiologist.

IV. WORK PLAN

This section outlines the anticipated initial steps the EHDI Program will take during the first grant year. The problem is well defined and the strategies for change are clearly

identified. The outcomes of each cycle will be tested in the next Plan-Do-Study-Act cycle later in the first year or during subsequent years.

Quality Improvement Strategy #1: Scripting the message to give the parents when an infant does not pass the initial screening

Activities	Start Date	End Date	Who		
A. Convene meeting of hospital newborn	April 08	June 08	EHDI staff		
hearing screening managers to discuss			Hospital		
strategies to reduce the percentage of infants			representatives		
lost to follow-up					
B. Establish a working group to develop the	June 08	October 08	EHDI staff		
script for the message to parents when an			Hospital		
infant does not pass the initial screening			representatives		
C. Develop a survey for message users and	June 08	October 08	EHDI staff		
parents after using the scripted message			Hospital		
			representatives		
D. Develop and distribute via email the draft	July 08	September	EHDI staff		
script for the message for parents and surveys		08	Hospital		
for feedback from potential hospital users			representatives		
E. Select the site, leader, and staff member(s)	October 08	November	Hospital		
to pilot test the scripted message for parents		08	representatives		
F. The leader will collect, summarize and	December	February	Hospital staff		
share the feedback from participants in the	08	09			
pilot testing					
G. Discuss the survey results with the	February	April 08	EHDI staff		
working group and plan next cycle	08		Hospital		
Evaluation Plane Treat shances in the person	Evaluation Plan: Track changes in the percentage of infants receiving rescreen				
A. Date of meeting with hospital newborn hear			creen		
B. Date of meeting with work group	ing screening	managers			
C. Date message was sent to managers					
D. Date survey was to managers					
E. Start date for pilot testing					
F. Date feedback given to working group					
G. Review the results of pilot testing, make changes as needed, then use the revised scripted message again					
scripted message again					

Quality Improvement Strategy #2: Scripting the message to give parents when an infant does not pass the rescreen

Activities	Start Date	End Date	Who		
A. Convene meeting of hospital newborn	April 08	June 08	EHDI staff		
hearing screening managers to discuss	1		Family		
strategies to reduce the percentage of infants			advocate		
lost to follow-up			Hospital		
			representatives		
B. Establish a working group to develop the	June 08	October	EHDI staff		
script for the message to give parents when		08	Family		
an infant does not pass the rescreen			advocate		
			Hospital		
			representatives		
C. Develop and distribute via email the draft	July 08	September	Consulting		
script for the message for parents		08	Audiologist		
			Family		
			Advocate		
			Hospital		
			representatives		
D. Develop a survey for feedback from	July 08	September	Consulting		
hospital users		08	Audiologist		
			Family		
			Advocate		
			Hospital		
			representatives		
E. Pilot test the reminder call message with	October 08	November	Family		
parents for a brief period of time		08	Advocate		
F. Review and discuss survey results with	December	February	Family		
the working group	08	09	Advocate Diagnostic		
			Center		
			Scheduler		
Evaluation Plan: Track changes in the percer	tage of infant	s receiving di			
A. Date of meeting with the hospital newborn hearing screening managers					
B. Date of meeting with work group					
C. Date draft script sent to hospital newborn h	nearing screen	ing managers			
· · ·	D. Date draft feedback survey sent to hospital newborn hearing screening managers				
E. Start date for pilot testing					
F. Review the results of pilot testing and surveys, make changes as needed, then test the					
scripted message again					

Quality Improvement Strategy #3: Using a fax form to alert infant's health care provider of screening results and the need for prompt follow-up

Activities	Start	End Date	Who			
A. Convene meeting of hospital newborn hearing screening managers to discuss strategies to reduce the percent of infants lost to follow-up	Date April 08	May 08	EHDI staff Hospital representatives Physicians			
B. Establish a working group to develop the hospital-specific fax form	July 08	September 08	EHDI staff Hospital representatives Physicians			
C. Develop a survey for fax users	July 08	September 08	EHDI staff Hospital representatives			
D. Develop a survey for fax receivers	July 08	September 08	EHDI staff Hospital representatives			
E. Pilot test the hospital-specific fax form, the survey for fax users and the survey for fax receivers	October 08	November 08	Hospital representatives			
F. Discuss fax use and survey results with the working group and hospital managers	December 08	February 09	EHDI staff Hospital representatives Physicians			
Evaluation Plan: Track changes in the per						
A. Date of meeting with the hospital newb	2	<u> </u>	agers			
B. Date of meeting with work group met to develop the fax form						
C. Date survey of fax users began						
D. Date survey of fax recipients began						
	E. Date pilot testing of fax form beganF. Review the results of pilot testing and user surveys, make changes as needed, then test					
the fax form again	ser surveys, n	nake changes	as needed, then test			

Quality Improvement Strategy #4: Verifying the identity of the infant's health care provider before parents leave the hospital

Activities	Start Date	End Date	Who	
A. Obtain baseline information for entry of	April 08	May 08	EHDI staff	
community health provider in Auris records				
from a sample of hospitals				
B. Add name of infant's health care provider	June 08	July 08	EHDI staff	
to the required data entry fields in the Auris			Auris IT staff	
tracking system				
C. Notify the hospital data entry staff that the	August 08	September	EHDI staff	
name of the infant's health care provider, not		08		
the physician of record in the hospital, will				
be a required field and start date				
D. Assess the number of infant's health care	October 08	November	EHDI staff	
providers entered in the Auris tracking		08		
system				
Evaluation Plan: Track changes in the percentage of correct infant's health care				
providers entered in the Auris tracking system				
A. Date when baseline data was compiled				
B. Date of change to require infant's health care provider in the Auris tracking system				
C. Date when the EHDI Coordinator posted the notice to make the community care				
provider a required in the Auris tracking system				
D. Review the effectiveness of change at samp	ole hospitals			

Quality Improvement Strategy #5: Reminder calls before diagnostic testing appointments that include reasons why the appointment is important

Activities	Start Date	End Date	Who			
A. Discuss strategies to reduce the percent	April 08	June 08	EHDI staff			
of infants lost to follow-up at one of the			Family			
regularly scheduled meetings with			Advocate			
Diagnostic Center audiologists			Diagnostic			
			Center			
			Audiologists			
B. Determine the average number of	April 08	June 08	EHDI staff			
infants who missed their appointment each						
month before making reminder calls						
C. Develop and distribute via email a draft	July 08	September	EHDI staff			
script for the reminder call message and		08	Family			
			Advocate			
D. Develop a survey to obtain feedback	July 08	September	EHDI staff			
from staff using the script		08	Family			
			Advocate			
E. Pilot test the reminder call message	October 08	November	Family			
with parents		08	Advocate			
			Diagnostic			
			Center			
			Scheduler			
F. Determine the number of infants who	December	February	Family			
missed their appointment each month after	08	09	Advocate			
making reminder calls			Diagnostic			
			Center			
			Scheduler			
	Evaluation Plan: Track changes in percentage of infants receiving diagnostic testing					
A. Date of meeting of diagnostic center aud						
B. The average number of infants who r	nissed an app	ointment for	diagnostic testing			
before reminder calls were initiated						
C. Date draft script was sent	C. Date draft script was sent					
D. Date survey was sent						
E. Start date for pilot testing	E. Start date for pilot testing					
F. Calculate the difference between the average number of infants who missed an						
appointment for month before and the number after reminder calls were initiated						

Quality Improvement Strategy #6: Obtaining consent for release of information at first contact with Family-Centered Early Supports and Services (FCESS) this is the title for Early Intervention programs in New Hampshire

Activities	Start Date	End Date	Who	
A. Meet with staff at specialized FCESS	April 08	May 08	EHDI staff	
program for young children with hearing			Family Advocate	
loss to discuss ways to notify the EHDI				
program of the date of enrollment				
B. Develop a plan to obtain consent for	June 08	July 08	EHDI staff	
release of information to the EHDI			Family Advocate	
Program at first contact with FCESS				
C. Pilot test the plan for a short time period	August 08	Oct 08	Family Advocate	
D. Discuss how the process is working at a	November	December	EHDI staff	
regularly scheduled meeting of EHDI staff	08	08	Family Advocate	
and the Family Advocate				
Evaluation Plan: Track changes in the percentage of infants known to be enrolled in				
FCESS				
A. Date EHDI staff and family advocate d	iscussed obtai	ning consent	to release date of	
enrollment in FCESS				
B. Date plan was finalized				
C. Start date for pilot testing				
D. Review the results of pilot testing, make changes as needed, then utilize the procedure				
with all new contacts for FCESS				

V. RESOLUTION OF CHALLENGES

Challenges are likely to be encountered in developing and implementing the activities of the work plan. For Strategies #1-4, the activities related to hospital newborn hearing screening programs, it is possible that hospital newborn hearing screening managers will be too busy to attend meetings. The EHDI staff will schedule the meetings at times and places convenient for the hospital program managers. The hospital managers who do attend the meetings may not be able to reach a consensus. The EHDI staff and the hospital managers are used to working with groups and experienced in the art of compromise and conflict resolution. If required, a knowledgeable colleague in the NH Department of Health and Human Services will be asked to assist the working group. The activity or tool chosen for the pilot test may not be successful which will prolong the process and delay the anticipated improvements.

The Plan-Do-Study-Act cycle is designed to test a change and act on the results. It is a scientific method used for action-oriented learning, which should readily lead to another change improvement that can be tested. The recommended changes may not be feasible in all NH hospitals. If needed, a change cycle will be developed for the situation in another hospital. Implementing the selected activity or tool may not be feasible in some NH hospitals without systemic changes or training for hospital personnel. Issues

presented at any hospital will be specifically addressed with the hospital's program manager.

Finally, managers of hospital newborn hearing screening programs not represented on the working group may be unwilling to implement the plan developed by that working group. All interested hospital staff members will be invited to attend the meetings, to give feedback on the proposed activity or tool, and to use the Model for Improvement in their hospital program.

The activities chosen for the pilot test in the diagnostic centers also may not be successful which will prolong the process and delay the anticipated improvements. Staff at each diagnostic center will conduct pilot testing. The Plan-Do-Study-Act cycle will be used to develop a plan that works in each diagnostic center.

The family advocate creates a link between the NH EHDI program and families of infants who do not pass their newborn hearing screening. She interacts with families in various stages of the hearing screening process. Infants born at most New Hampshire hospitals receive an initial hearing screening and, if needed, a rescreen prior to leaving the hospital. These families receive an appointment for diagnostic testing at the time of discharge. Because of the technology used at three New Hampshire hospitals, other infants who do not pass their newborn hearing screening leave the hospital with an appointment to return for a rescreen. Because of equipment failures, fussiness or early discharges, some infants are discharged from the hospital without a newborn hearing screening. Families in each of these groups need to take specific steps to ensure that their infant has a hearing screening. The family advocate contacts these families and helps them obtain the services their infant needs.

For Strategy #6, receiving consent to notify the EHDI Program of enrollment in the FCESS, the FERPA rules for release of information may hinder the notification of the NH EHDI program of enrollment in FCESS. The FCESS and EHDI Programs may need to establish an interagency agreement to permit the sharing of information between the programs.

Currently, there are only two diagnostic centers in New Hampshire. Attachment C provides a map of New Hampshire Hospitals with Birth Facilities and Audiology Diagnostic Centers. In August 2007, the center located in the Audiology Department at Dartmouth-Hitchcock Medical Center stopped accepting referrals from birth hospitals in the southern part of the state. Most families live within an hour's drive of this center. However, during the winter, the drive is longer because some roads are not maintained in winter. The other center is in the seacoast area of the state. Families within an hour's drive often use this center. Families in the southwestern part of New Hampshire are a two-hour drive from either center. Since this area is near the Massachusetts border, families may choose to have their infant tested at a Massachusetts diagnostic center. The list of centers approved by the Massachusetts Department of Health has been shared with staff at hospital newborn hearing screening programs.

Most New Hampshire hospitals are able to recruit nurses and nursing assistants to conduct newborn hearing screenings. However, the turnover rate is high at some hospitals, which means the loss of experienced screeners and a constant need for staff training. Most newborn hearing screening managers are nurses who oversee the birth units. They often remain in their positions for several years. In any year, approximately three of 23 hospitals need to recruit a new manager. However, the manager position at one hospital has been vacant for more than a year. An experienced staff nurse has coordinated the program with the assistance of the hospital's audiology department. From May 2006 to the present, the number of diagnostic centers decreased from seven to two. Three centers decided to discontinue offering infant testing. Resignations of the only audiologists trained in infant testing resulted in the removal of two centers from the list of diagnostic centers.

VI. EVALUATION AND TECHNICAL SUPPORT CAPACITY

MCH RESOURCES

Programs throughout the Division of Public Health Services have used performance measures for contracts with agencies throughout New Hampshire. Since the implementation of the Auris tracking system in 2004, the EHDI coordinator and the consulting audiologist have used performance measures to evaluate the hospital newborn hearing screening programs and help program managers to identify areas for improvement. The performance measures were developed with the assistance of the QA clinical specialist within the Maternal and Child Health Section.

With the help of the MCH QA Clinical Consultant, the EHDI Program staff established performance measures to address the quality assurance activities for all aspects of the newborn hearing screening process. The QA Clinical Consultant will be available to assist the EHDI program staff when they address the quality improvement strategies to reduce the number of infants and families who are lost to follow-up following a failed hearing screening.

The MCH epidemiologist has helped the EHDI staff utilize the data available in the Auris tracking system. The MCH staff developed the concept of a data linkage model, centered on the establishment of an MCH Data Mart, which will house all of the linked databases and facilitate data analysis. It is anticipated that Phase I, integrated birth data, will be available in the MCH Data Mart in early 2008. As the MCH Data Mart evolves, the EHDI coordinator will be better positioned to understand and evaluate the impact of the EHDI program on the health and well being of New Hampshire residents.

WORKING COMMITTEE ACTIVITIES

The EHDI staff and the members of the working group will start with the QI strategies developed by NICHQ. We will use the Plan-Do-Study-Act process for the activities outlined in the Section IV. Work Plan. This method allows a group to test and implement changes in the workplace. Initially, the changes will be tested on a small scale for a

specific time period or a limited number of events. If the change is not successful, the group will act on the results to plan another change cycle. Once we have results, members of the working group will share the results for testing in other facilities. In this way, all facilities can improve the outcomes for infants throughout New Hampshire.

Another useful resource in the Department of Health and Human Services, Division of Public Health Services is the personnel in the Bureau of Policy and Performance Management. The EHDI coordinator is an active member of the Public Health Improvement Team co-chaired by Joan Ascheim, Chief of the Bureau of Policy and Performance Management and Lisa Bujno, Chief of the Bureau of Community Health Services. Both have been the project director for this grant and are former Title V Directors. The Public Health Improvement Team members will serve as consultants in the change process and provide feedback on the activities of the working groups.

VII. ORGANIZATIONAL INFORMATION

The EHDI Program is housed within the New Hampshire Title V program in the Maternal and Child Section (MCHS) of the Bureau of Community Health Services, Division of Public Health Services, Department of Health and Human Services. The Maternal and Child Health Section has historically been devoted to administering health programs and services for women, infants and children. It is supported in part by Title V funds.

The MCHS is well positioned to continue universal 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. The EHDI Program is now in its seventh year and newborn hearing screening is offered in all New Hampshire hospitals with birth facilities.

Patricia Tilley, is the MCHS Administrator, and has over 10 years of experience working with families. Ms. Tilley will continue to serve as project director. Audrey Knight, RN, MSN, is the Child Health Nurse Consultant for MCH, with 21 years of experience in her role. Ms. Knight will manage activities of the program, 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. Mary Jane Sullivan, Consulting Audiologist, will continue to work in the program. The program coordinator and the program specialist will manage the tracking and follow-up components 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.

The EHDI Program Coordinator and Consulting Audiologist will build on the close working relationships developed with hospital screening staff as well as with audiologists throughout New Hampshire. The EHDI staff has assisted the hospital newborn hearing screening managers to identify areas needing improvement and monitor the progress of each hospital program toward these goals. The EHDI AAP champion, Dr. Joseph Vitterito, has enthusiastically embraced his role of promoting newborn hearing screening among New Hampshire pediatricians and other health care professionals.

There are several related programs within the MCHS, together encompassing 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 Childhood Lead Poisoning Prevention Program provides case management; environmental inspections of residences; surveillance of all cases of elevated lead in young children statewide; and works closely with health care providers and communities to assure appropriate clinical care and safe environments for children.

Other current MCHS initiatives complement and support the activities of the EHDI Program. The main goal of the State Systems Development Initiative (SSDI) is to develop linkages between various data sets within and outside of MCHS. In support of this goal, the SSDI Program Planner directed the work with Dennis Cassily, business systems analyst from the Office of Information Technology, to develop a comprehensive, integrated system of linked data sets. In 2005, Mr. Cassily developed a linkage of New Hampshire birth certificates with EHDI screening files in order to ensure that all newborn are offered hearing screening. Later, information in the Newborn Screening Program reporting system, another MCHS program, was linked with birth certificate data. Recently, Mr. Cassily began developing the MCH Data Mart. It is anticipated that Phase I, integrated birth data, will be available in the MCH Data Mart in 2008. The MCH Data Mart will house all of the linked databases and facilitate analysis by MCH staff. This comprehensive, integrated system of linked data sets that will assist in fulfilling several critical public health functions: identification of infants not screened for hearing and metabolic disorders, identification of disparities among the prenatal population receiving MCHS-funded community-based services and among other MCH populations in the state, and evaluation of the effectiveness and accessibility of health services provided by the MCHS. The MCHS epidemiologist will use the MCH Data Mart to provide in-depth analysis for the EHDI program.

MCHS has also played a vital role in the development of a birth conditions surveillance system for New Hampshire. This project, initiated within MCHS as a neural tube defects registry in 2000, has grown into a comprehensive, active surveillance system to track major birth conditions. MCHS has worked closely with Dartmouth Medical School 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.

In addition, the EHDI Program can call on the expertise and assistance of its sister

organization, the Special Medical Services Unit, New Hampshire's agency for Children with Special Health Care Needs (CSHCN). The Special Medical Services Unit has a long history of providing care coordination for children with chronic conditions. A representative of the Special Medical Services Unit is a member of the EHDI Advisory Committee. Staff from the Special Medical Services Bureau is available to provide care coordination and financial assistance for income-eligible families, including families of children identified as deaf or hard of hearing.

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 Committee on Administrative Rules adopted rules that require anyone conducting newborn hearing screenings or diagnostic hearing evaluations must report the results to the 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. It should be noted that despite the lack of a legislative mandate, all hospitals with birth facilities offer newborn hearing screening. In 2006, 99.4% of infants born at a New Hampshire hospital were offered a newborn hearing screening.

In summary, the New Hampshire EHDI Program has the capacity to continue providing excellent service to infants born in New Hampshire and their families. All New Hampshire hospitals with birth facilities participate on a voluntary basis to evaluate their performance in newborn hearing screening. Screening rates remain high and continue to grow. Parents have support and voice through the Family Advocate. Although we are challenged by the lack of diagnostic centers, everyone remains committed to timely screening, diagnosis and follow-up. The New Hampshire EHDI program expects that these new strategies to reduce loss to follow up will only strengthen our maturing newborn hearing screening system.