

RHODE ISLAND UNIVERSAL NEWBORN HEARING SCREENING

PROGRAM NARRATIVE - TABLE OF CONTENTS

Purpose of the Project pages 1- 3

Needs Assessment..... pages 3 - 5

Data Requirements.....pages 5- 6

Identification of Target Population pages 6 - 7

Goal and Objectives pages 7 - 8

Project Methodology.....pages 8 - 16

Collaboration and Coordination.....pages 16 - 22

Administration and Organization.....pages 22 - 24

Organization Experience, Capacity, and available Resources.....pages 25 - 29

Appendix A - KIDSNET Diagram pdf attachment

 Medical Home Algorithm..... pdf attachment

 Work Plan Matrix pages 30 – 34

Appendix B - Job Descriptions of Key Personnel..... pages 35 – 38

Appendix C - Biographical Sketches of Key Personnel..... pages 39 – 42

Appendix D

 Copies of existing contracts..... pdf attachment

 Descriptions of Existing Contracts pages 43 – 44

Appendix E - Project Organizational Chart..... page 45

Appendix F - Letters of Support..... pdf attachment

Program Narrative

PURPOSE OF THE PROJECT

Having achieved high newborn hearing screening rates in Rhode Island that consistently exceed 99% and a low initial fail rate of just under 2%, the Rhode Island Hearing Assessment Program (RIHAP) has focused recent attention on assuring that 1) each infant referred for diagnostic audiological evaluation receives it by 3 months of age, and 2) every infant identified with hearing loss is enrolled in a program of early intervention and family support by 6 months of age. Assuring that each baby referred for diagnostic testing receives it in a timely manner is, of course, critical to achieving timely intervention.

RIHAP currently has evidence that in 2003, 70 of 74 infants referred for diagnostic testing actually followed through. In 2002, 46 of 53 referred received diagnostic audiological evaluation. Over that two year period, that is 91%. In addition to less than 100% completion of the diagnostic evaluation, only 61% of these infants completed the diagnostic process by 3 months of age, as recommended by the Joint Commission on Infant Hearing (JCIH). That means that for 9% of infants referred, there is no record of diagnostic evaluation and for 30%, the evaluation occurred after 3 months of age. Furthermore, the only follow-up currently done for infants who pass the initial screen but have identified risk factors for hearing loss is one letter to the parents at 6 months of age, despite American Academy of Pediatrics 2000 position statement which recommends diagnostic evaluation every 6 months until age 3.

Three critical partners help facilitate the diagnostic audiological evaluation. These are families, audiologists, and medical homes. Each of these partners must be aware of the need as

well as understand and value the importance of timely follow-up testing for each baby referred for diagnostic audiological evaluation.

Recent and ongoing related collaborative efforts with newborn hearing screening partners, including other Title V, Part C and Children with Special Health Care Needs (CSHCN) programs, include education about the newborn hearing screening process among pediatric primary care providers as well as sharing newborn hearing screening and diagnostic audiological test results with authorized individuals involved in care coordination for a child through an integrated child health data system known as KIDSNET (see Appendix A).

The purpose of this project is to build on these existing and past efforts to continue to raise awareness about the screening process and the importance of following through with diagnostic evaluation upon referral. Since much of our earlier work has been with medical homes, this project will focus on ways to reinforce that message with families, particularly Spanish speaking families. In addition, this project will continue to reach out to the pediatric community.

Beyond English language informing materials distributed in the maternity hospitals, letters to families written only in English, and some very outdated and minimal information on the RIHAP and HEALTH websites, only the labor intensive personal outreach is available. To address this gap, and with the hope that better awareness and understanding will lead to the anticipated benefit of increasing the numbers of diagnostic evaluations completed following referral from newborn hearing screening, we propose to 1) modify a medical home algorithm of the hearing screening and diagnostic process into a family friendly format for distribution to families; 2) update and overhaul two state-wide websites (Rhode Island Department of Health

and Women & Infants' Hospital) with information on newborn hearing screening in English and Spanish; 3) make informational materials available in Spanish; 4) translate letters to parents into Spanish; 5) provide reminders regarding audiological monitoring of infants with hearing risk factors every 6 months until age 3 and evaluate the effectiveness of such a strategy; and 6) present findings from recently completed medical home survey and medical home algorithm at grand rounds.

NEEDS ASSESSMENT

Rhode Island is a small urban state with a total population of 1,048,319 and approximately 13,500 births annually. Approximately 18% of these births are to Hispanic mothers. Rhode Island has seven maternity hospitals with more than half of occurrence births occurring at Women and Infants Hospital, the regional perinatal center. All seven maternity hospitals have been screening newborns for hearing loss since 1994. Screening rates exceed 99%, with approximately 1.8% being referred on for diagnostic audiological testing. Recent data related to newborn hearing screening are presented in Table 1. Over a two year period, 91% of infants referred are known to have had diagnostic audiological testing, although only 61% were tested by age three months.

Table 1

Year/ # live births	# failed screening/ referred for audiologic assessment	# with documented diagnostic audiologic testing	# diagnosed with hearing loss	# enrolled in Early intervention	# enrolled in Early Intervention by 6 months of age
2003/ 13,823	74	70 (49 before 3 months of age)	19	17	17
2002/ 13,546	53	46 (29 before 3 months of age)	23	19 (estimate)	13 (estimate)

In 2003, an addition to the 73 infants referred immediately for diagnostic ABR, 374 were referred on for Visual Response Audiometry (VRA) at six months of age due to medical condition or other risk factors.

Data collected through the Pregnancy Risk Assessment Monitoring Survey (PRAMS) revealed that among mothers of infants born in 2002, 89% were aware that their baby had a hearing screen in the hospital. However, when the data are analyzed by ethnicity, only 69% of Hispanic mothers were aware of the hearing screening compared to 93% of non-Hispanic mothers being aware. It is possible that this disparity in awareness could lead to lower compliance with follow-up and prompts a closer look at languages spoken.

Table 2: 2003 Birth Cohort (13,823) by Language Spoken

English	Spanish	French	Chinese	Portuguese	Cam-bodian	Laotian	Other	Un-known
12,721	916	23	15	69	13	18	42	6

As this table reveals, Spanish is by far the most common language spoken in Rhode Island after English and accentuates the importance of having Rhode Island specific information about newborn hearing screening available in Spanish. The program will address other less commonly spoken languages in other ways.

Finally, a recent round of focus groups were held with pregnant women and new moms to ascertain what information women wanted to learn about newborn public health services, in what format, at what point in time and from whom the information should be delivered. Groups were held with both English and Spanish speakers. Not surprisingly, Spanish speakers desired information in their native tongue. In addition, results of the focus groups led to the design of an integrated newborn screening brochure that includes information about newborn hearing

screening, newborn blood (metabolic, endocrine, hemoglobinopathy) screening, developmental risk assessment, home visiting, KIDSNET, and birth defects registry. The brochure has been modified slightly into three versions – one prenatal, one perinatal, and one postnatal – as the desired information varies slightly at each time point.

DATA REQUIREMENTS

The Rhode Island Newborn Hearing Screening Program has capacity to collect and report the required data on an on-going basis. Rhode Island has already been reporting annually the number of live births in the state, the number of infants screened prior to hospital discharge, the number of infants suspected of a hearing loss with an audiologic diagnosis by 3 months of age and the number of infants diagnosed with a hearing loss enrolled in a program of early intervention before 6 months of age. This data is reported annually to the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA). A recent upgrade of the newborn hearing screening tracking system (RITRACK) includes data fields for all of this information. The RITRACK data system is linked to KIDSNET, one of the most critical resources available to this project for data analysis. KIDSNET is a population based public health data system with information on children's preventive health services into which all Rhode Island children born on or after January 1, 1997 were entered at birth. Currently it links data from nine different early childhood public health programs into one child record (see Appendix A). KIDSNET allows for on-line, point-of-service access by primary care providers and other authorized users. Through KIDSNET, and using immunization and lead screening information as a proxy, it is possible to ascertain if children with hearing loss have a medical home. It is also possible to verify participation in a program of Early Intervention (Part C) with

family-to-family support. Because birth certificate information is also linked through KIDSNET, it is possible to look at this information in various ways, such as by race, ethnicity and gender.

The Division of Family Health, in which the Newborn Hearing Screening Program resides, has already begun reporting maternal and child health performance measures electronically through the Title V Information System (TVIS). The Data and Evaluation Unit will be available to provide data or technical assistance needed for the required Maternal Child Health Bureau performance measures and administrative reporting related to this project.

IDENTIFICATION OF TARGET POPULATION

The proposed activities target three important populations with means to improve the communication to them regarding the importance of timely diagnostic audiological evaluation following referral from newborn hearing screening.

The first target population is all pregnant women, their partners, and new parents. This includes the approximately 13,000 couples who conceive and give birth each year. Parents-to-be and new parents are inundated with information both during the pregnancy and hospital stays. This can often be overwhelming and newborn hearing screening is just one of many important topics.

Currently, a brochure called “Sound Beginnings” is placed in an infants’ pram following the hearing screening. It describes the screening process and what will happen if a referral for diagnostic audiological evaluation takes place. This brochure will be replaced with the integrated newborn screening brochure described earlier. Other sources of information about the screening process and importance of follow-up are websites at the Department of Health and

Women & Infants' Hospital, as well as the better developed national websites of the National Center for Hearing Assessment and Monitoring (NCHAM) and Boys Town National Research Hospital (babyhearing.org). Further reinforcement is provided by the infants' medical homes.

The second target population is a subpopulation of the first group. As described earlier, approximately 18% of the birth cohort is Hispanic. According to newborn developmental risk assessment data, 7% of the entire birth cohort are known to speak Spanish in the home.

However, this is felt to be an underestimate since language is sometimes documented as English and home visitors find the family speaks Spanish. As described above in the needs assessment, far fewer (69%) Hispanic women recently giving birth were aware of newborn hearing screening compared to non-Hispanic women (93%) and focus groups identified information in Spanish as critical need. Initial funding for the integrated newborn screening informing project did not include funding for translation and testing in Spanish, which is proposed in this application.

The third target population is pediatric primary care providers. Previous work includes surveying the needs of this population and development of a Rhode Island medical home flow diagram (appendix A), a modification of the American Academy of Pediatric Medical Home guidelines for infants with hearing loss. This work was achieved through collaboration with the Rhode Island AAP, and the state's two AAP- Early Hearing Detection and Intervention (EHDI) champions, Dr. Betty Vohr and Dr. Robert Burke.

GOALS AND OBJECTIVES

Following are the goals and objectives of the proposed project. Activities, methods and evaluations will be described in the methods section.

Goal 1: All infants' referred for diagnostic audiological evaluation will complete the evaluation by three months of age

Objective 1.1: Increase the percentage of mothers of newborns who are aware of newborn hearing screening from 89% to 95% by the end of December, 2007

Objective 1.2: Increase the percentage of Hispanic mothers of newborns who are aware of newborn hearing screening from 69% to 90% by the end of December, 2007

Objective 1.3: Increase the percentage of infants known to have had diagnostic audiologic evaluation following referral from newborn screening from 91% to 100% by December, 2007

Goal 2: Late onset hearing loss will be identified promptly

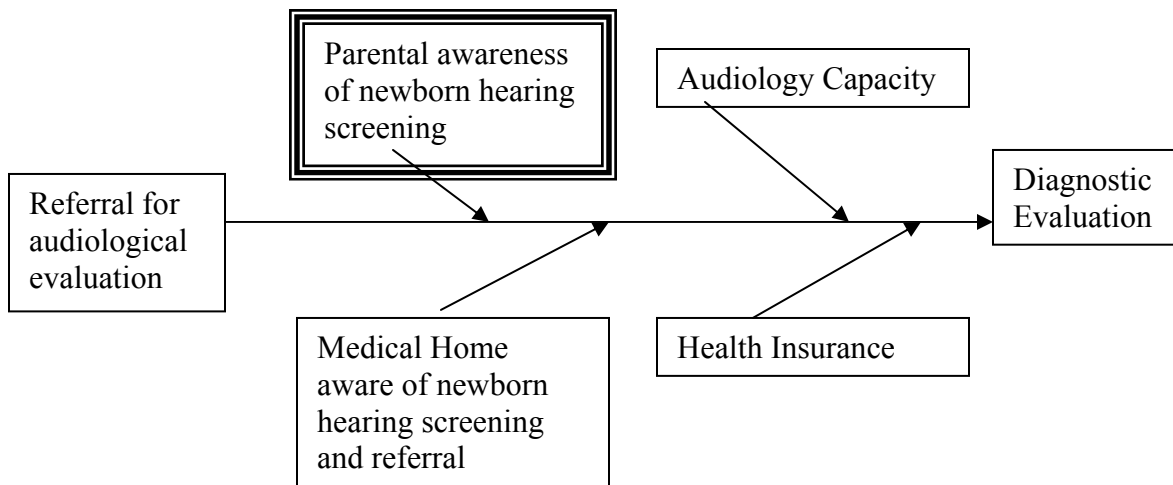
Objective 2.1: All infants born after June 1, 2005 who pass the newborn hearing screening with risk factors for late onset hearing loss will receive ongoing audiological monitoring until at least 3 years of age

PROJECT METHODOLOGY

Goal 1: All infants' referred for diagnostic audiological evaluation will complete the evaluation by three months of age

This is the overarching goal of the project, reflecting the priority focus of the grant guidance. There are multiple factors affecting whether or not an infant referred from newborn screening actually completes a diagnostic audiological evaluation, and in particular by age 3 months. Among these are system capacity, access to health insurance, transportation, and awareness on the part of parents and medical home provider of the need for timely audiological evaluation. Previous grants activities have addressed pediatric audiologist capacity and awareness of medical home providers. Rhode Island also has relatively high rates of insured

children through private insurance and Medicaid managed care. The activities of this proposal will focus on increasing awareness among new moms, particularly those who are Spanish speaking. The assumption behind this logic is that parental awareness is an important mediator in completion of diagnostic evaluation.



A detailed description of the work plan is provided in appendix A.

Evaluation: A recent upgrade of RITRACK, Rhode Island’s newborn hearing screening tracking system, included considerable expansion for recording diagnostic audiology results, dates, and final diagnosis. In addition, KIDSNET is in the process of giving pediatric audiologists access to newborn hearing screening records and creating a mechanism for on-line reporting of diagnostic results which will be linked back to the newborn RITRACK record. Thus, the information system technology is in place to monitor progress toward achieving 100% completion of audiological evaluation following referral from newborn screening as the objectives of the project are completed over time.

Objective 1.1: Increase the percentage of mothers of newborns who are aware of newborn hearing screening from 89% to 95% by the end of December, 2007

As described above, the focus of this project will be on increasing awareness of newborn hearing screening among new parents. Three primary methods will be used.

- 1) Modify a medical home algorithm of the hearing screening and diagnostic process into a family friendly format for distribution to families.

Recent work resulted in the development of a flow diagram (Appendix A) for medical homes caring for infants who are referred from newborn hearing screening in Rhode Island. This will be distributed to the primary care provider of record along with the infants' newborn hearing screening result and recommendations for follow-up. While it is important that the primary care provider understand the resources and process, this algorithm was developed specifically for primary care providers and is not in a format that would be family friendly and easily understood. An interdisciplinary work group of Early Intervention providers, Family Guidance, audiologists, newborn hearing screening staff and families recently overhauled Rhode Island's Guide to Hearing Loss, a resource for families following the diagnosis of permanent hearing loss. This work group, a subcommittee of the Rhode Island Hearing Assessment Program (RIHAP) Advisory Follow-up Committee, will be tapped to modify the Medical Home algorithm into a family friendly format. Leadership for the project will come from Carol Dorros, a parent consultant to newborn hearing screening who led the development of the medical home version. Professional expertise for the production, including testing a draft on a sample of parents, will be available through the Division of Family Health's communications contract. Once completed,

the family friendly flow diagrams will be distributed along with letters sent to parents when a referral for diagnostic evaluation is made.

2) Update and overhaul two state-wide websites (Rhode Island Department of Health and Women & Infants' Hospital) with information on newborn hearing screening

Rhode Island began screening infants for hearing loss over ten years ago, when the internet was just in its infancy. Information related to newborn hearing screening was eventually included in both the Department of Health and Women & Infants' Hospital websites. However, this information is somewhat outdated, is not comprehensive, and has never been tested on new parents for comprehension. Furthermore, they do not take advantage of the potential for links to well developed websites on newborn hearing loss such as NCHAM (infanthearing.org) and babyhearing.org from Boys Town National Research Hospital. Working with the RIHAP Advisory Committee, which includes parents, as well as the Division of Family Health's communications contractor and the "webmasters" of each site, these two websites will be reviewed, updated, overhauled and tested.

3) Present findings from recently completed medical home survey at grand rounds and continue to distribute and discuss the Medical Home Newborn Hearing Screening Algorithm.

This activity is proposed as an indirect means of reaching parents through their infants' medical home. It is important that both primary care providers and parents know the resources and process for follow-up from newborn hearing screening. If primary care providers understand that parents will have a similar guide to the one they received, they can reinforce what should happen and the importance of timely follow-up. Carol Dorros and AAP EHDI Champions Betty

Vohr, MD and Robert Burke, MD, would all be able to present a grand rounds on this topic and are valuable assets to this project.

Evaluation: Awareness of newborn hearing screening was added as an optional state discretionary question to the Pregnancy Risk Assessment Monitoring Survey (PRAMS), a survey of a representative sample of mothers with new infants conducted through states under direction of the Centers for Disease Control. This survey is conducted by the Division of Family Health, Data and Evaluation Unit, on an ongoing basis and will be used to monitor progress on this objective.

Objective 1.2: Increase the percentage of Hispanic mothers of newborns who are aware of newborn hearing screening from 69% to 90% by the end of December, 2007

A plausible explanation for the lower awareness of newborn hearing screening among Hispanic mothers is that information is not available in Spanish. To address this problem, the project will:

1) Make informational materials available in Spanish.

As described earlier, an integrated newborn screening brochure that includes information about newborn hearing screening, newborn blood (metabolic, endocrine, hemoglobinopathy) screening, developmental risk assessment, home visiting, KIDSNET, and birth defects registry is close to completion. Three versions – one prenatal, one perinatal, and one postnatal – will be produced. This brochure will be translated into Spanish. The translation process will be handled by the Division of Family Health's Communications Unit and will include initial translation, back translation, and testing on Spanish speaking new moms. These will then be distributed to obstetricians, maternity hospitals, and pediatric care providers for use with Spanish speaking

families. Maternity hospitals will leave one in the pram following the hearing screening according to current protocol. The Family Guidance Program, which guides parents of infants with hearing loss as they learn about their child's diagnosis, communication development and options and provides mental health and family-to-family support has a brochure which will be translated into Spanish as well.

2) Translate letters to parents into Spanish.

The Rhode Island Hearing Assessment Program uses 25 letters that are used to communicate with parents about various aspects of follow-up from newborn hearing screening, including referral for diagnostic audiological evaluation. These letters will also be translated into Spanish using the methods described above. The Spanish translation will be printed and sent to homes when KIDSNET indicates that Spanish is the language spoken or ethnicity is Hispanic. This information will be downloaded from KIDSNET into RITRACK to avoid manual look-up of this information.

3) Provide information on the web at two state-wide websites (Rhode Island Department of Health and Women & Infants' Hospital) on newborn hearing screening in Spanish as well as links to Spanish info at other web sites.

Once the web sites have been overhauled in English, a Spanish version will be produced. A national search of information in Spanish will be conducted so as to take advantage of already existing links and information. As described above, this will be accomplished working with the RIHAP Advisory Committee, the Family Guidance Program which serves many Spanish speaking families, the Division of Family Health's Communications Unit and the "webmasters" of each site.

Evaluation: Awareness of newborn hearing screening was added as an optional state discretionary question to the Pregnancy Risk Assessment Monitoring Survey (PRAMS), a survey of a representative sample of mothers with new infants conducted through states under direction of the Centers for Disease Control. Ethnicity, as reported by the mother, is collected. This survey is conducted by the Division of Family Health, Data and Evaluation Unit, on an ongoing basis and will be used to monitor progress on this objective.

Objective 1.3: Increase the percentage of infants known to have had diagnostic audiologic evaluation following referral from newborn screening from 91% to 100% by December, 2007

It is possible that some infants have received audiological evaluation but that the results have not been communicated to RIHAP. Working with a Pediatric Audiology Task Force, KIDSNET and RIHAP are developing a diagnostic reporting screen in KIDSNET using funding from the CDC. The RIHAP Administrator will work with the KIDSNET data manager to download this information into RITRACK. Although parental awareness is the main focus of this project, making reporting easy may also improve instances of unreported diagnostic audiology results.

Evaluation: RITRACK keeps track of all diagnostic audiology results. This data is reported annually to the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA) and will be used to track the progress toward this objective and the overall goal.

Goal 2: Late onset hearing loss will be identified within 6 months of onset in infants born after June 1, 2005

Objective 2.1: All infants born after June 1, 2005 who pass the newborn hearing screening with risk factors for late onset hearing loss will receive ongoing audiological monitoring until at least 3 years of age

Currently, RIHAP mails reminders to parents and primary care providers regarding the importance of audiological monitoring of infants who pass the newborn hearing screen but have risk factors for hearing loss. Last year, VRA at six months was recommended for 374 infants. In these situations, visual response audiometry (VRA) is recommended every 6 months until age 3, per the American Academy of Pediatrics 2000 Position Statement. However, resources only permit one initial reminder. Now that an effective mechanism for reporting audiologic testing through KIDSNET is close to completion, it will be possible to monitor the effectiveness of a more aggressive reminder process. RIHAP will continue to notify parents every six months by mail, until a child reaches 3 years of age. An existing KIDSNET report sent to Medical Homes includes infants who are due for immunization and lead screening. This report will be modified to include notification of Medical Homes, as defined as the last primary care provider to administer vaccine to a child, of the need for VRA every 6 months.

Evaluation:

To evaluate the effectiveness of this strategy, two cohorts of infants will be compared using data in the RITRACK data system. The percentage of the 374 infants born in 2003 completing VRA testing at 6, 12, 18, 24, 30 and 36 months will be compared to the percentage completing VRA testing at 6, 12, 18, 24, 30 and 36 months among infants born from June 1, 2005 to May 31, 2006. The second cohort would receive the intensive reminders, while the first group has not. Further evaluation will include looking at the numbers/percent from each group diagnosed with

hearing loss and the average time and time range from newborn hearing screening and most recent VRA. If the more intensive reminding appears to result in earlier diagnosis and intervention for late onset hearing loss, it will be recommended for adoption as ongoing program policy.

COLLABORATION AND COORDINATION

The organizational base for this project is the Rhode Island Department of Health, Division of Family Health, Office of Children's Preventive Services. William H. Hollinshead, MD, MPH is both Medical Director of the Division of Family Health and Title V Director for the State and is responsible for all newborn screening, Children with Special Health Care Needs and Early Intervention, Part C. Associate Medical Director, Peter R. Simon, MD, MPH provides support to all newborn screening programs as well as to Part C. Both will provide leadership and guidance for the project. Also in the Division of Family Health are KIDSNET, the Communications Unit, and the Data and Evaluation Unit. These key collaborators are described below. A letter of support from Dr. Hollinshead on behalf of Family Health and Title V is included in appendix F.

EARLY INTERVENTION (PART C) / OFFICE OF FAMILIES RAISING CHILDREN WITH SPECIAL HEALTH CARE NEEDS - The Early Intervention (Part C) program, is currently located within the Division of Family Health in the Office of Families Raising Children with Special Health Care Needs. The organizational proximity of the Part C program to the Newborn Hearing Screening Program and mutual leadership lends itself to collaboration. There is a long history of collaboration between these two programs. In fact, the Newborn Hearing Screening Program was developed with extensive involvement of Early Intervention leadership and service providers. Ellen Amore, the Newborn Screening Program Manager and proposed project

director, meets regularly with Deborah Garneau, Chief of the Office of Families Raising Children with Special Health Care Needs and Part C Coordinator to discuss related activities and find potential areas for collaboration. A letter of support from Deborah Garneau is included in appendix F. Additionally, Early Intervention is well represented on the Rhode Island Hearing Assessment Advisory Committee described below. Due to a legislative mandate, the Part C program will be transitioned to the Department of Human Services. Deborah Garneau has been heavily involved in preparing for that move and will facilitate a connection between this project and a new Part C coordinator when that person is named.

KIDSNET - KIDSNET is an integrated information system which supports tracking and follow-up for nine mandated pediatric preventive services programs: Newborn Screening for poor developmental and health outcomes under Part C IDEA, Blood Spot Newborn Screening, RIHAP, WIC, EI, Lead Screening, Immunization, Home Visiting, and Automated Vital Statistics. KIDSNET now offers electronic access to pediatric primary care sites in RI where children receive vaccines, thus providing a comprehensive child health profile to medical homes. Newborn hearing screening data is available to primary care providers who participate in KIDSNET. On-line diagnostic reporting for audiologists is in development. Because KIDSNET is located within the same division (Family Health) and office (Children's Preventive Services) as the Newborn Hearing Screening Program, mutual leadership and close professional relationships foster collaboration with this program. Ellen Amore, who is the proposed Project Director, is actually responsible for establishment of records in KIDSNET as a result of newborn developmental risk assessment and birth certificate data downloads. All newborn data (newborn

hearing screening, blood spot, birth certificate, developmental risk assessment) is cross checked in KIDSNET to assure that all infants have been screened.

COMMUNICATIONS UNIT - The Communications Unit of the Division of Family Health provides support to all Family Health programs. Services available include translations, brochure development, media campaigns, web-site development, publications, printing and focus groups. In addition to in-house communications professional staff, the Communications Unit has a contract with an outside media firm.

DATA AND EVALUATION UNIT - The Data and Evaluation Unit of the Division of Family Health provides support to all Family Health programs. All reporting for Title V and other Maternal Child Health Bureau and Centers for Disease Control and Prevention childhood data requests are completed by this unit. The unit is staffed with epidemiologists, data and evaluation experts.

THE RHODE ISLAND HEARING ASSESSMENT PROGRAM (RIHAP) - In 1993 Rhode Island became the first state in the nation to mandate universal newborn hearing screening. RIHAP, based at Women and Infants Hospital in Providence, carries out that public mandate on a daily basis under contract with the Department of Health (appendix D). The four primary goals of RIHAP include administration of universal newborn hearing screening at each of the 7 birthing hospitals in the state, facilitating early diagnostic identification of permanent hearing loss, providing smooth transitions to Early Intervention and education services, and collaborating with parents and professionals.

Following established protocols, newborns are screened by either well- trained hospital technicians or nurses in the hospital nursery using transient evoked otoacoustic emissions

(TEOAE). Infants who do not pass this screen, and have an immediate automated auditory brain stem response (AABR) screen and do not pass, now become part of the RITRACK database tracking system for follow up. Infants who pass and have a medical risk factor (Joint Committee on Infant Hearing Year 2000 Position Statement) are also tracked and referred for diagnostic visual response audiometry (VRA) at six months of age. Infants who pass and do not have a medical risk factor are discharged from the program.

At Women and Infants' Hospital, a RIHAP audiologist reviews and interprets all screening results. RIHAP's information management system, RITRACK, supports the program by generating reminders to families of their follow up needs, and by tracking patient access to services and outcomes for quality improvement. RIHAP also uses KIDSNET's home visiting program to encourage compliance with follow-up activities when families do not respond to RIHAP letters or phone messages.

Two committees contribute to this system of screening and follow up services: 1) *The Rhode Island Infant Hearing Screening Advisory Committee* is mandated to provide regulatory oversight to RIHAP. Committee membership includes representatives from audiology, pediatrics, special education, insurance, the deaf community, hospital neonatal nurseries and the Rhode Island Department of Health. A quarterly report is made to the RI Director of Health. 2) *The Rhode Island Infant Hearing Screening Follow-Up Committee* addresses practical issues facing parents of and professionals working with children who have hearing loss. Committee membership includes representatives from HEALTH, families with children with hearing loss, the deaf community, family physicians, pediatrics, audiologists in private practice and institutional settings, the Rhode Island Department of Education, the University of Rhode Island

Communications Disorders Department and advocacy groups. The mission is to identify and address gaps in services and to ease access to services including evaluation, intervention, and habilitation for families and professionals. A subcommittee is an integral part of the RIHAP/EI Quality Review process for children identified through RIHAP with hearing loss. A letter of support from Dr. Betty Vohr, Director of RIHAP, is included in appendix F.

RI SCHOOL FOR THE DEAF - FAMILY GUIDANCE PROGRAM - The Family Guidance program serves children with hearing loss, birth to age 3 years in Rhode Island through contracts negotiated with Early Intervention (Part C) service providers. Staffed by teachers of the deaf, speech language pathologists, educational audiologists and language specialists, it offers an array of center-based and home-based services individually designed for each family and child's unique needs. Services include parent support groups, family training to develop effective communication with their child, speech-language-auditory activities, sign language classes, coordination and participation in the IFSP and IEP plans. The mission is to provide families with guidance and information, which will support them in making decisions and advocating for their child. It is designed to enhance parents' competence and strives to reflect the culture, values, and social characteristics of which the family is a part. The Family Guidance Program has a close relationship with the Newborn Hearing Screening Program. Infants diagnosed with permanent hearing loss are referred to Family Guidance and Part C. Family Guidance serves on several newborn hearing advisory committees and is collaborating with the Department of Health Newborn Hearing Screening Program on two research projects and several system development initiatives. This program is a critical link for the project to families of children with hearing loss. A letter of support from Mary Jane Johnson, Director of the Family Guidance Program, is

included in appendix F. Marianne Ahlgren, PhD, works part-time in the Family Guidance Program. It is proposed that she contribute approximately five hours per week to this project to help coordinate activities involving families.

RI PEDIATRIC AUDIOLOGY TASK FORCE - The RI Pediatric Audiology Task Force, is comprised of representatives from hospital audiology departments, private practices and large Otolaryngology group practices. This group has worked with the Newborn Hearing Screening Program on several important issues, including the need for an easy reporting mechanism for diagnostic audiological evaluation results to RIHAP and medical homes. As a result, on-line reporting through KIDSNET is now being developed, so that results will be communicated to the newborn hearing screening program and will be readily available to medical homes. This state-wide group will be an important partner in implementing and promoting use of this valuable reporting tool which will enhance tracking capacity of diagnostic results following referral.

AMERICAN ACADEMY OF PEDIATRICS (EHDI CHAMPIONS) – Rhode Island is honored to have two “EHDI Champions”. This initiative of the national American Academy of Pediatrics seeks to assign at least one Early Hearing Detection and Intervention champion in each state to promote the importance of newborn screening and timely follow-up among their peers and serve as a liaison between the pediatric and “EHDI” communities. Dr. Betty Vohr, Director of the Rhode Island Hearing Assessment Program, and Dr. Robert Burke are Rhode Island’s EHDI champions. Dr. Vohr conducted pioneering work in newborn hearing screening, has published extensively on the subject, and has been a tireless leader and advocate for newborn hearing screening, in Rhode Island, the country, and internationally. She recently worked on development of an AAP “pedialink” module for newborn hearing screening. Dr. Burke is a

pediatrician specializing in caring for children with special health care needs. Both Drs. Vohr and Burke were involved in a recent survey of primary care provider attitudes about the role of the medical home for children with hearing loss and in development of the Rhode Island Medical Home algorithm for children referred following newborn hearing screening. Their connections with the Rhode Island chapter and national AAP facilitated development of the Rhode Island medical home algorithm for newborn hearing screening (appendix A). This project includes development of a family friendly version, thus making them ongoing important collaborators in this work.

ADMINISTRATION AND ORGANIZATION

Since the 1993 legislative session in Rhode Island mandated universal newborn hearing screening, the Rhode Island Department of Health (HEALTH) has been working to integrate the RI Hearing Assessment Program (RIHAP) with other components of newborn screening mandated under existing state or federal law. Programmatic responsibilities for newborn screening in RI (hearing, bloodspot, Part-C/Childfind) have been consolidated in the Division of Family Health, in the Office of Children's Preventive Services under our KIDSNET unit, which is working to integrate all newborn screening data (hearing, blood spot, developmental risk) in a way that facilitates communication and coordination among newborn screening programs, primary care providers (Medical Homes), and specialty care providers. RIHAP is run by Women & Infants' Hospital under contract with the Department of Health. The Family Guidance Program at the Rhode Island School for the Deaf, provides family support and guidance related to hearing loss and communication under contracts with Early Intervention service providers. All of these programs are described above in the Collaboration and Coordination Section. See

appendix E for an organizational chart depicting the administrative organization of the proposed project.

Organizational Structure at HEALTH: Within HEALTH, the Division of Family Health (DFH) is organized into five sections: Office of Children's Preventive Services (OCPS), Office for Families Raising Children with Special Health Care Needs (OFRCSHCN) which includes Early Intervention (EI) Part C, Office of the Supplemental Food Program for Women, Infants and Children (WIC), Adolescent and Young Adult Health Unit (AYA), and the Office of the Medical Director (OMD), which includes the Parent Consultant Program, Communications Unit, Data and Evaluation Unit, and Fiscal and Administration Unit.

The OCPS oversees the KIDSNET, Newborn Hearing Screening, Newborn Blood Spot Screening, Newborn Developmental Risk Assessment, and Lead Screening Programs. Program management, administration, daily operations, and long term planning for these programs are approached in a coordinated manner and integrated where feasible. KIDSNET receives data from all of the above programs as well as Immunization, EI, WIC, and the Family Outreach Home visiting program. The Office of Vital Records within the Division of Management Services also updates KIDSNET with birth certificate data.

One aspect of KIDSNET, which does not reside in the Division of Family Health, is technical oversight of the information system itself. HEALTH has a centralized Office for Information Systems (OIS) located in the Division of Management Services. Information System staff are assigned to KIDSNET. This arrangement keeps the program aspects in the Division where that expertise lies while allowing the technical components to be overseen by individuals with information system expertise.

Organizational Structure of RIHAP and Women and Infants Hospital:

Women and Infants Hospital is part of the Care New England system of care providing services to families in Rhode Island, southeastern Massachusetts and eastern Connecticut and is committed to providing comprehensive women's and newborn health care. The Rhode Island Hearing Assessment Program (RIHAP) is part of Women and Infants Hospital's Department of Pediatrics, and is directed by HEALTH to manage the state-wide newborn hearing screening program. RIHAP staff is directly responsible to the RIHAP Medical Director, the Chief of the Department of Pediatrics, and to hospital administration.

Newborn hearing screening is provided at each of the seven Rhode Island birthing hospitals by each hospital's own trained staff. However, only the RIHAP staff based at Women and Infants' manage the screening data and follow up procedures for infants who failed or missed their hearing screens, or for infants with medical risk factors who will be followed after hospital discharge. In a collaborative effort, the RIHAP Medical Director, Audiologists and Program Administrator provide screening equipment and supplies, and training and support to the hearing screening staffs at all of Rhode Island's birthing hospitals. Additionally, all hospitals receive regular quality review reports and are included in the program's quality improvement initiatives. Ultimately, hearing screen data from all Rhode Island newborns is provided to the Department of Health through the state-wide KIDSNET data system.

Organizational Structure of the Rhode Island School for the Deaf: The Rhode Island School for the Deaf is part of the RI Department of Education and provides education for children with hearing loss from birth through high school. The Family Guidance Center, the Hearing Center and the First Connections program are based at the RI School for the Deaf.

ORGANIZATION EXPERIENCE, CAPACITY AND AVAILABLE RESOURCES

With over 10 years of experience screening all newborns for hearing loss, the Rhode Island Department of Health (HEALTH), Division of Family Health and its partners Women and Infants' Hospital, RI Hearing Assessment Program (RIHAP), and the RI School for the Deaf Family Guidance Program, are well positioned to carry out the objectives described in this application. The proposed program staff are highly experienced and have participated in the implementation and development of universal newborn hearing screening in Rhode Island since its inception.

FAMILY HEALTH – The Division of Family Health has strong leadership and support for universal newborn hearing screening. Medical Director and Title V Director William Hollinshead and Associate Medical Director Peter Simon were both instrumental in bringing newborn hearing screening to Rhode Island and continue to support the development and improvement of the program. They also have promoted data integration efforts through KIDSNET, resulting in a critical connection to medical homes. They have been advocates for newborn hearing screening, data integration, and other maternal and child health activities at both the state and federal levels.

Other strong leadership in the Division of Family Health includes Deborah Garneau, MS, Chief, Office of Families Raising Children with Special Health Care Needs, and Amy Zimmerman, MPH, Office Chief of Children's Preventive Services which includes KIDSNET and Newborn Screening. Ellen Amore, MS, has been Newborn Screening Manager for over four years. She is responsible for newborn hearing screening, developmental risk assessment and blood spot screening and for assuring that records on

all newborns are opened in KIDSNET and all infants have received each of these important newborn services. Because Newborn Hearing Screening, KIDSNET, Children with Special Health Care Needs, communications and data and evaluation programs are all within the same organizational division, with common oversight, strong existing relationships and a history of working together collaboratively, the project is well positioned for successful implementation.

KIDSNET- One of the most critical resources available to this project and upon which much of the data integration and reporting will depend is KIDSNET. KIDSNET is a population based public health data system with information on children's preventive health services into which all Rhode Island children born on or after January 1, 1997 were entered at birth. Currently it links data from nine different programs into one child record (see Appendix A). KIDSNET allows for on-line, point-of-service access by primary care providers and other authorized users, such as the newborn hearing screening program, Early Intervention (Part C), Head Start, and audiologists. By cross checking newborn data sources, KIDSNET is the mechanism through which tracking and quality assurance activities for the completion of newborn hearing screening, blood spot screening, birth certificate, and developmental risk assessment are accomplished. . Furthermore, because of the integrated nature of KIDSNET, medical homes, child health programs, Early Intervention (part C), audiologists, specialty care providers, Head Start, School Nurse Teachers, home visitors, and other authorized users can access information necessary for case management and tracking of children with hearing loss and other public health concerns. In addition, reports can be generated to notify parents, medical homes, and others of the need for follow-up services for an individual child.

COMMUNICATIONS UNIT – As described above, the Communications Unit of the Division of Family Health provides support services such as translations, brochure development, media campaigns, web-site development, publications, printing and focus groups. They have strong working relationships with the Department web site manager, as well as translation, printing, and publishing resources in the state. In addition to in-house communications professional staff with years of collective communications experience, the Communications Unit has a contract with an outside media firm. This unit will be critical to the completion of Spanish translation, web-site upgrades, and family friendly medical home algorithm production.

DATA AND EVALUATION UNIT - As reported earlier, the Data and Evaluation Unit provides support to all Family Health programs. All reporting for Title V and other Maternal Child Health Bureau and Centers for Disease Control and Prevention childhood data requests are completed by this unit. The unit is staffed with epidemiologists, data and evaluation experts. They will be available to assist with the MCH reporting requirements as well as the evaluation portion of this project.

WOMEN & INFANTS' HOSPITAL – RI Hearing Assessment Program

Betty R. Vohr, M.D., Medical Director of RIHAP, will continue to oversee the Rhode Island Hearing Assessment Program and provide guidance for all newborn hearing screening activities. Mary Catherine Hess, MA, RIHAP Administrator, is a critical participant in the project with regards to data reporting and tracking and follow-up of infants who have been referred for diagnostic evaluation or for monitoring due to risk factors for late onset hearing loss. She has recently worked to coordinate a significant upgrade of the newborn hearing screening tracking database (RITRACK) which has resulted in major improvements in the ability to track and

follow-up individual infants. She is also the program liaison with KIDSNET, and coordinates with KIDSNET data managers to assure that all infants born in Rhode Island have been screened. She is involved in efforts to improve reporting of diagnostic audiological testing to RIHAP, using KIDSNET as an electronic link between audiologists and RITRACK. She works with the RIHAP audiology coordinator who is responsible for supervision of all newborn hearing screening, interpretation of results, and reporting quality indicators.

RITRACK

RITRACK, RI Hearing Assessment Program's information system, tracks all births through a two stage screening process to referral for diagnostic audiology. At Women and Infants' Hospital, RIHAP staff process and manage that site's screening results daily. There, patient demographic information is downloaded from the hospital database into the "RITRACK" database daily, and actual computerized screening results for any given infant are available immediately to the audiologist on site. At the other six birthing hospitals, data is submitted via courier once a week on hand written forms and computer disks to the central RIHAP site at Women and Infants' Hospital for data entry and a sometimes lengthy process of matching and downloading into RITRACK. Efforts are underway to automate an electronic transfer of this information to RITRACK. The RIHAP audiologist reviews and interprets all screening results. RITRACK then generates reminders to families and medical homes of follow up needs, and tracks patient access to services and outcomes for quality improvement. RIHAP also uses KIDSNET's home visiting program to encourage compliance with follow-up activities when families do not respond to letters or phone messages.

RITRACK is the means through which this project will be able to report data related to completeness of timely diagnostic evaluation and enrollment in a program of early intervention and family support. RITRACK recently underwent a major upgrade to allow tracking through the diagnostic process and to make audiological testing results available to medical homes, Early Intervention and others through KIDSNET. Current efforts related to this project include 1) linkage with audiologists and otolaryngologists through KIDSNET, 2) electronic reporting of initial newborn screening results to RITRACK, 3) pre-population of database with demographic information from an integrated electronic birth certificate/developmental risk assessment system, and 4) connection through KIDSNET to results from the RI Department of Education Statewide School Screening Program for ascertainment of late onset infant and toddler hearing loss.

RI SCHOOL FOR THE DEAF - FAMILY GUIDANCE PROGRAM

As described earlier, the Family Guidance program serves children birth to age three with hearing loss by offering an array of center-based and home-based services including parent support groups, family training to develop effective communication with their child, speech-language-auditory activities, weekly sign language classes, coordination and participation in the IFSP and IEP plans. Staff include teachers of the deaf, speech language pathologists, educational audiologists and language specialists. Family Guidance Director, Mary Jane Johnson M.S., has been involved since the early days in newborn hearing screening in Rhode Island. Marianne Ahlgren, PhD, works with families in the Family Guidance Program and will be the coordinator of project activities which rely on family involvement and input.

Appendix A: Tables, Charts, etc.

A KIDSNET diagram is attached electronically in pdf format.

Medical Home Algorithm is attached electronically in pdf format.

Work Plan Matrix – Rhode Island Universal Newborn Hearing Screening

Goal 1: All infants’ referred for diagnostic audiological evaluation will complete the evaluation by three months of age

Objective 1.1: Increase the percentage of mothers of newborns who are aware of newborn hearing screening from 89% to 95% by the end of December, 2007

1) Modify a medical home algorithm of the hearing screening and diagnostic process into a family friendly format for distribution to families.

Strategy/ Activity	Year			Outputs
	1	2	3	
Identify families to provide input through Family Guidance Program	X			List of families willing to participate
Redefine and convene Medical Home Algorithm Workgroup	X			Work Group member list
Develop final draft based on medical home algorithm	X			Final Draft of Family Friendly Algorithm
Test draft among families for comprehension		X		Results and recommendation documented
Revise based on test results and recommendations		X		Final Draft
Layout, type set, and print final version		X		
Implement distribution to Families through RIHAP and Family Guidance		X		Final printed version of family friendly algorithm

- 2) Update and overhaul two state-wide websites (Rhode Island Department of Health and Women & Infants' Hospital) with information on newborn hearing screening

Strategy/ Activity	Year			Outputs
	1	2	3	
Develop Communication Goals for Web-Sites	X			Documented goals
Review existing information on other web-sites	X			Results of review
Work with RIHAP Advisory Committee, Family Guidance Program and families to identify best links	X			List of selected links for sites
Edit existing information to meet communication goals and connect to links	X			Draft web content
Test draft with families to assess if communication goals were met		X		Results and recommendations based on test of draft
Complete upgrade of web-sites		X		Upgraded Newborn Hearing Screening Websites at Dept of Health and Women & Infants' Hospital

- 3) Present findings from recently completed medical home survey at grand rounds and continue to distribute and discuss the Medical Home Newborn Hearing Screening Algorithm.

Strategy/ Activity	Year			Outputs
	1	2	3	
Distribution of Medical Home Algorithm with screening results through RIHAP	X	X	X	
Present medical home survey findings	X			List of talks given
Present Family Friendly Algorithm			X	List of talks given

Objective 1.2: Increase the percentage of Hispanic mothers of newborns who are aware of newborn hearing screening from 69% to 90% by the end of December, 2007

1) Make informational materials available in Spanish.

Strategy/ Activity	Year			Outputs
	1	2	3	
Translate newborn hearing screening and Family Guidance brochures into Spanish	X			Draft translated brochure
Back translate into English to assess quality – revise and repeat as needed	X			Back translation
Produce draft brochures in Spanish		X		Draft brochures
Test on Spanish speaking parents		X		Results of test
Revise and finalize based on test results			X	
Layout, type set, and print final version			X	Final Spanish version brochures
Distribute via obstetricians, maternity hospitals, medical homes, Family Guidance, RIHAP			X	

2) Translate letters to parents into Spanish.

Strategy/ Activity	Year			Outputs
	1	2	3	
Translate all letters to families generated by RITRACK	X			Draft translated letters
Back translate into English to assess quality – revise and repeat as needed	X			Back translations
Produce draft letters in Spanish		X		Draft letters
Test on Spanish speaking parents		X		Results of test
Revise and finalize based on test results		X		Final Spanish version of letters

Strategy/ Activity	Yr 1	Yr 2	Yr 3	Outputs
Program RITRACK to accept language spoken in home from KIDSNET	X			
Program RITRACK to print out Spanish version if language spoken is Spanish		X		Programming complete
Implement distribution of Spanish version letters			X	

3) Provide information on the web at two state-wide websites (Rhode Island Department of Health and Women & Infants' Hospital) with information on newborn hearing screening in Spanish as well as links to Spanish info at other web sites.

Strategy/ Activity	Year			Outputs
	1	2	3	
Translate website information into Spanish		X		Draft translated letters
Back translate into English to assess quality – revise and repeat as needed		X		Back translations
Review existing Spanish information on other web-sites		X		Results of review
Work with RIHAP Advisory Committee, Family Guidance Program and Spanish speaking families to identify best links		X		List of selected links
Produce draft Spanish Web Pages		X		Draft web pages
Test on Spanish speaking parents		X		Results of test
Implement Spanish Web pages		X		Upgraded Newborn Hearing Screening Websites at Dept of Health and Women & Infants' Hospital to include Spanish information

Objective 1.3: Increase the percentage of infants known to have had diagnostic audiologic evaluation following referral from newborn screening from 91% to 100% by December, 2007

Strategy/ Activity	Year			Outputs
	1	2	3	
Audiologist able to send diagnostic results through KIDSNET	X			Audiology page in KIDSNET (this is being done under another grant)
Program download of results from KIDSNET to RITRACK		X		Results transfer successfully to RITRACK

Goal 2: Late onset hearing loss will be identified within 6 months of onset in infants born after June 1, 2005

Objective 2.1: All infants born after June 1, 2005 who pass the newborn hearing screening with risk factors for late onset hearing loss will receive ongoing audiological monitoring until at least 3 years of age

Strategy/ Activity	Year			Outputs
	1	2	3	
Develop modification of 6 month reminder letter to be sent at 12, 18, 24 , 30 and 36 months	X			Modified versions of reminder letter
Program KIDSNET to include risk factors for late onset hearing loss	X			Risk factors can be viewed in KIDSNET
Implement mailing reminders to infants turning 12, 18, 24, 30, 36 months	X			Reminders are mailed
Modify KIDSNET report to medical homes to include infants needing VRA	X			Medical Home Report with list of infants needing VRA
Evaluation			X	

Appendix B: Job Descriptions for Key Personnel

Project Manager – Ellen Amore, MS

Duties and Responsibilities:

- Provide overall project management
- Point of contact for communications with HRSA
- Grant management including budget and reporting
- Establish necessary cooperative agreements and contracts
- Liaison to RITRACK and KIDSNET data systems
- Coordinate work with Early Intervention (Part C), Rhode Island Hearing Assessment Program, Communications and Data and Evaluation Units
- Other duties as needed

Qualifications and Experience:

- Graduation from a masters level university program of recognized standing, concentration in maternal child health, public health, or related field preferred
- At least 3 years professional/management experience
- Experience working with newborn hearing screening
- Experience working with pediatric medical homes
- Knowledge of computer and relational databases
- Expertise in EXCEL, WORD, POWERPOINT, and Windows
- Strong communication and written documentation skills
- Ability to work independently with minimal supervision as well as with a team
- Successful management of large scale projects

Project Family Coordinator – Marianne Ahlgren

Duties and Responsibilities:

- Provide coordination for project activities related to families
- Serve as liaison between project director, audiologists and Family Guidance Program
- Recruit and coordinate family involvement in all aspects of project
- Other duties as needed

Qualifications and Experience:

- Graduation from a masters level university program of recognized standing, preferably with a concentration in speech language pathology, audiology, or a related field
- At least 3 years professional audiology experience
- Experience working with families of infants with hearing loss
- Experience working with pediatric medical homes
- Extensive knowledge of communication and language development
- Strong communication and written documentation skills
- Ability to work independently with minimal supervision as well as with a team

Parent Consultant/ Physician Liaison – Carol Dorros, MD

Duties and Responsibilities:

- Act as a representative to the project of a wide range of families of children with permanent hearing loss
- Act as liaison between project and pediatric primary care providers
- Work with other families to develop family friendly depiction of the Rhode Island Newborn Hearing Screening and Follow-up process
- Advise project on issues related to families
- Serve as a family representative in State Early Hearing Detection and Intervention activities and advisory groups
- Other duties as needed

Qualifications and Experience:

- Parent of a child with hearing loss
- MD degree with experience working with Rhode Island Pediatric Community
- Knowledge of the Rhode Island newborn hearing screening and follow-up system
- Experience with programs of family to family support, including Early Intervention (Part C)
- Basic computer skills such as email, WORD, and Windows
- Strong verbal and written communication skills
- Ability to work independently with minimal supervision as well as with a team

RIHAP Administrator – Mary Catherine Hess

Duties and Responsibilities:

- Provide overall administration for newborn hearing tracking and follow-up
- Responsible for all aspects of electronic tracking (RITRACK)
- Reporting all data related to newborn hearing screening, diagnostic audiological evaluation, and participation in Early Intervention, Part C
- Coordinate project activities related to implementation and evaluation of intensive follow-up of hearing infants with risk factors for late onset hearing loss

Qualifications and Experience:

- Graduation from a masters level university program of recognized standing, concentration in audiology, speech and language, or related field preferred
- At least 3 years professional/management experience
- Experience working with newborn hearing screening
- Experience working with pediatric medical homes
- Expertise with computers and relational databases
- Expertise in ACCESS, EXCEL, WORD, POWERPOINT, and Windows
- Strong communication and written documentation skills
- Ability to work independently with minimal supervision as well as with a team
- Successful administration of large program involving data, tracking and follow-up

3) Appendix C: Biographical Sketches of Key Personnel

All key personnel are currently on staff of the current HRSA Universal Newborn Hearing Screening grant.

Biographical Sketch

Name: Amore, Ellen	Title: Manger, Rhode Island Newborn Screening Programs	Birth Date: 11/29/61
-----------------------	--	-------------------------

Education

Institution and Location	Degree	Year Completed	Field of Study
Harvard School of Public Health, Boston, MA	MS	1994	Maternal and Child Health
Stanford University, Stanford, CA	AB	1983	Human Biology Concentration in Child Development

MAJOR PROFESSIONAL INTERESTS: Maternal and Child Health,

Newborn Screening, Genetics

Research and Professional Experience:

Manager, Newborn Screening	2000- present
Manager, Home Visiting Program	1995- 2000
Program Associate, Univ. of CT, Center for Environmental Health	1988-1992
Research Assistant (Yale, UCONN)	1983 - 1987

Biographical Sketch

Name: Dorros, Carol	Title: Parent Consultant/ Physician liaison	Birth Date: 4/26/59
------------------------	---	------------------------

Education

Institution and Location	Degree	Year Completed	Field of Study
Boston Univ. School of Medicine, Boston, MA	MD	1987	General Medicine
Washington University, St. Louis Mo	BA	1981	Biology

MAJOR PROFESSIONAL INTERESTS: Internal Medicine, Maternal and Child Health,

Newborn Hearing Screening

Research and Professional Experience:

Parent Consultant/Physician Liaison

Newborn Hearing Screening 2001- present

Practicing Physician, Internal Medicine

Harvard Pilgrim Health Care, Warwick RI 1992 - 1996

General Medicine

Notre Dame Ambulatory Clinic, Central Falls RI 1990-1992

Resident, Internal Medicine 1987- 1990

Biographical Sketch

Name: Mary Catherine Hess	Title:	Birth Date: 7/24/75
------------------------------	--------	------------------------

Education

Institution and Location	Degree	Year Completed	Field of Study
Gallaudet University, Washington, DC	MA	1998	Linguistics
University of Texas, Austin, TX	BS	1996	Communication Sciences and Disorders

MAJOR PROFESSIONAL INTERESTS: Linguistics, Computational Linguistics,
 English as Second Language, Education of the Deaf

Research and Professional Experience:

Administrator, RI Hearing Assessment Program

Women & Infants Hospital	2001- present
Outreach Specialist, RI Relay	2002 – present
Freelance Sign Language Interpreter	2001 – present
High School English Teacher	
The Learning Center for Deaf Children	1999-2000

Appendix D: Description(s) of Proposed/Existing Contracts.

Women & Infants' Hospital

The Rhode Island Hearing Assessment Program (RIHAP), based at Women and Infants Hospital in Providence, carries out the public mandate to screen all newborns on a daily basis under contract with the Department of Health. The four primary goals of RIHAP include administration of universal newborn hearing screening at each of the 7 birthing hospitals in the state, facilitating early diagnostic identification of permanent hearing loss, providing smooth transitions to Early Intervention and education services, and collaborating with parents and professionals. This contract (electronic pdf copy attached) can be modified as needed to accommodate the activities of this project.

RI School for the Deaf – Family Guidance Program

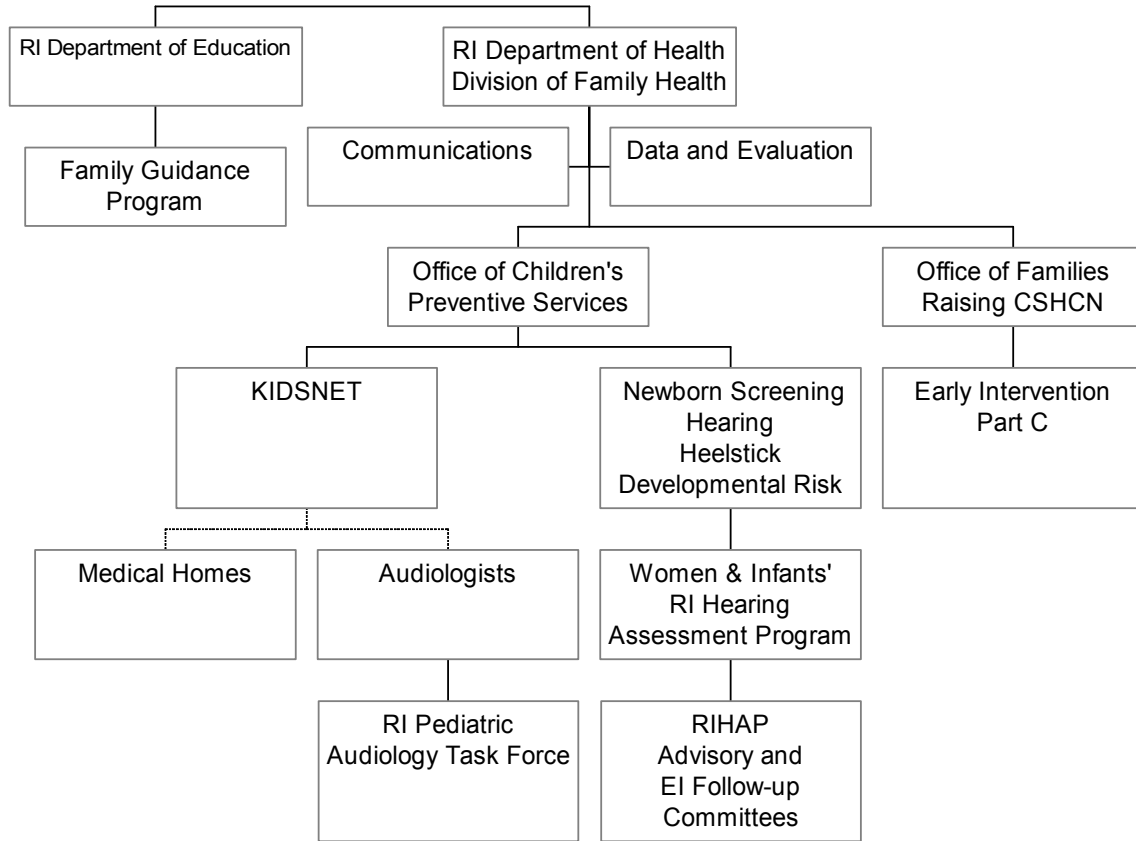
The Family Guidance program serves children with hearing loss, birth to age 3 years in Rhode Island through a cooperative agreement between the RI Dept of Health and the RI Dept of Education. Staffed by teachers of the deaf, speech language pathologists, educational audiologists and language specialists, it offers an array of center-based and home-based services individually designed for each family and child's unique needs. Services include parent support groups, family training to develop effective communication with their child, speech-language-auditory activities, weekly sign language classes, coordination and participation in the IFSP and IEP plans. The mission is to provide families with guidance and information, which will support them in making decisions and advocating for their child. The Newborn Hearing Screening Program has a long standing relationship with Family Guidance. An electronic pdf copy of an

existing cooperative agreement for two CDC funded EHDI research projects has been attached. This agreement could be modified to include activities of this project.

Hearing Rehabilitation Foundation (see www.hearf.org for details):

A contract has been established with the Hearing Rehabilitation Foundation to support existing EHDI program activities, including staff support, professional training, support to the EHDI system, planning, implementation and evaluation of mental health, audiological and medical home training programs. This not-for-profit organization was founded in 1995 to promote the provision of speech communication training for children and adults with hearing loss. They organize a large number of workshops for teachers, clinicians and other professionals involved in the education and management of children with hearing loss and have extensive experience developing and implementing assessment and training programs for children. This contract allows considerable flexibility and efficiency to project management and will include administrative and staff support to the project as well. The existing contract (electronic pdf copy attached) can be modified to include this project.

Appendix E: Project Organizational Chart



6) Appendix F: Other Relevant Documents

Letters of support are attached electronically in pdf format.

Key Words

Audiology

Children with Special Health Needs

Chronic Illnesses and Disabilities

Deafness

Early Childhood Development

Early Intervention

Family Centered Health Care

Family Professional Collaboration

Family Support Services

Hearing Loss

Hearing Screening

Hearing Tests

Individualized Family Service Plan

Infant Screening

Information Systems

Interagency Cooperation

Interdisciplinary Teams

Medical Home

Mental Health

Newborn Screening

Parent Professional Communication

Parent Support Groups

Parents

Primary Care

Professional Education in CSHN

Screening

Service Coordination

Surveys