Early Hearing Detection and Intervention (EHDI) Tracking, Surveillance, and Integration

Rhode Island Department of Health

April 2008

1.0 Background and Need

Rhode Island is a small urban state with a total population just above 1 million and an annual birth cohort of approximately 13,000. Rhode Island has seven maternity hospitals with more than half of all births occurring at Women and Infants Hospital, the regional perinatal center. RI General law 23-13-13 was passed in 1992 and implemented during 1993. This law requires that all infants born in Rhode Island be screened for hearing loss using procedures approved by the Department of Health. The law further requires that the screening be reimbursable by health insurers and creates a hearing screening advisory committee. All seven maternity hospitals have been screening newborns for hearing loss since 1994. The Department of Health contracts with Women and Infants' Hospital to coordinate newborn hearing screening and follow-up statewide. Screening rates exceed 99%, with under 2% being referred on for diagnostic audiological testing.

The Rhode Island Department of Health is the applicant agency. Within the Department of Health, there are four collaborating programs: KIDSNET, Newborn Screening, Maternal and Child Health (Title V), and Children with Special Health Care Needs. Key collaborators in other organizations include 1) the Rhode Island Hearing Assessment Program at Women & Infants' Hospital; 2) the Department of Human Services Early Intervention; and 5) the Rhode Island School for the Deaf. These will be described in detail in section 3.0 of this application.

<u>Data Systems and data reporting protocols</u>. Rhode Island is privileged to have two information systems to help facilitate tracking and follow-up for newborn hearing screening.

The first, RITRACK, is specific to newborn hearing screening. The second, KIDSNET, is an integrated data system that includes several newborn and early childhood preventive screening services.

RITRACK - RITRACK, RI Hearing Assessment Program's information system, tracks all births through a two-stage screening process to referral for diagnostic audiology and enrollment in Early Intervention. The RITRACK database is pre-populated daily with demographic information from KIDSNET originating in the electronic birth certificate system. In 2007, 78% of records were available within 2 days of birth and 96% within four days of birth. 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. Laptops using new OAE equipment have been purchased for the other birthing hospitals. USB flash drives are used to exchange data with RIHAP and upload to the central repository (RITRACK) in a standard format. This facilitates a cross check with birth data in KIDSNET to recall any infants who were discharged prior to having a hearing screen. 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 the Department of Health's home visiting program to encourage compliance with follow-up activities when families do not respond to letters or phone messages or when assistance with language or cultural barriers as indicated.

Diagnostic results reported to the EHDI program are recorded in RITRACK. Diagnostic results can also be entered on-line by audiologists in KIDSNET. Diagnostic information will be exchanged electronically in both directions between RITRACK and KIDSNET. Screening, diagnostic results and Early Intervention participation will then be available through KIDSNET to EHDI partners including primary care providers, Early Intervention, audiologists, and others.

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. Because KIDSNET is linked to the RITRACK system, it provides a mechanism for data exchange throughout the EHDI system, including to medical homes and other programs serving children with special health care needs. KIDSNET allows for secure, authenticated role-based, point-of-service access by primary care providers and other authorized users, such as the newborn hearing screening program, Early Intervention (Part C), audiologists, and Head Start via the internet. Electronic cross checking newborn data sources in 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), 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 to on-line access to newborn hearing screening results, primary care providers will soon be able to print a newborn report for their patients which summarizes newborn screening results and follow-up recommendations, hearing loss risk factors, newborn blood spot results, vaccinations, birth weight, and other information collected at the time of birth.

Newborn hearing screening information is well documented and integrated with vital records data. This creates the capacity to assure that all infants are screened and to report using various demographic criteria. Although many audiologists report diagnostic information voluntarily, not all diagnostic data is reported. In 2006, diagnostic information was missing on 12% (17 of 141) of the infants who did not pass the newborn hearing screen. Furthermore, Early Intervention (part C) participation can be linked to EHDI data via KIDSNET but non-part C intervention through the Family Guidance Program is not collected electronically. The proposed goals and objectives seek to enhance capacity to collect EHDI data, particularly diagnostic audiology and early intervention data, to appropriately share that information with partners such as medical homes that can help facilitate appropriate follow-up, and to broaden the scope and capacity for reporting EHDI data to all partners, including the CDC.

2.0 Work Plan:

Goals, objective and a description of proposed work associated with each follow. A detailed work plan table can be found in appendix F.

Goal 1: Enhance capacity to identify, match, collect and report standardized unduplicated individual EHDI data

Goal 1, Objective 1: Develop hospital screening data reporting and parent notification at hospitals and implement by June 30, 2011

The Joint Commission on Infant Hearing (JCIH) recommends that parents be notified of a failed hearing screen prior to discharge. In order to meet this recommendation, data must be entered at the time of screening to produce written notification. Existing forms used to report pass/fail, screening technology, and risk factors on paper (Sound Beginnings and NICU forms) will be adapted for electronic reporting and be programmed to produce a corresponding parent notification letter, with capacity to print in languages commonly spoken in Rhode Island. Screening teams at each hospital will be trained to report screening data electronically, print the letters, and when follow-up is needed, to schedule appointments and discuss the results and need for follow-up with parents.

Goal 1, Objective 2: Develop capacity to monitor the status of every occurrent birth through screening, audiologic evaluation, and early intervention by June 30, 2010

KIDSNET currently captures every occurrent birth in Rhode Island through integration with the electronic birth certificate. This is cross-checked in KIDSNET with screening data sent from the newborn hearing database (RITRACK) to assure all babies are screened. Recent enhancements to KIDSNET include the collection of diagnostic and Early Intervention (Part C) data. However, no information is available regarding participation in the Family Guidance Program, an important program in the Rhode Island EHDI system. The Early Intervention Program recently hired a teacher of the deaf to act as a single point of entry for infants and children with diagnosed hearing loss. She works with the Family Guidance Program to coordinate services. KIDSNET will be programmed to capture data on Family Guidance Program participation. We will also explore ways to collect data related to other services provided both from Part C and “non-Part C”, such as speech language pathology, and outcomes, such as language skills. Both Early

Intervention and Family Guidance receive diagnostic data that may not always be reported to the EHDI Program. Reports to monitor the status of each infant who did not pass the newborn hearing screen will be created and used to seek out missing diagnostic data and assure participation in Early Intervention and Family Guidance when appropriate.

Goal 1, Objective 3: Develop capacity to create the annual national EHDI data report electronically by June 30, 2010

Standardized unduplicated individual data needed to report to the national CDC EHDI data survey currently resides in both KIDSNET and RITRACK. Some amount of manual linking and matching is necessary to complete the final report. Regular data exchange with KIDSNET to collect all the required data and an automated report for CDC EHDI annual reporting will be programmed into RITRACK.

Goal 1, Objective 4: Develop and implement an EHDI data feedback plan by June 30, 2011

A large amount of EHDI data is now collected between RITRACK and KIDSNET. Many community partners in the EHDI system report this data but often do not benefit from any analysis of this data. Annual reports will be created to provide feedback to EHDI partners such as primary care providers, hospitals, audiologists, and Early Intervention. These reports will be site specific in addition to state-wide so that they may see how they compare. This will also be used as an opportunity to address loss to follow-up rates and perhaps secure information. Where applicable, the report may include blood spot data. The state-wide reports will be posted to the web.

Goal 2: Increase data sharing, integration and linkage

Goal 2, Objective 1: Make intended primary care provider available to EHDI partners through KIDSNET by June 30, 2011

Sharing EHDI data with primary care providers is an important component of follow-up as well as providing a medical home. EHDI partners such as RIHAP, Early Intervention and audiologists as well as primary care providers have access to KIDSNET. Currently, there is no primary care provider viewable in KIDSNET unless a vaccination has been given by a KIDSNET participating provider. This excludes a few in state providers as well as all out of state providers. For infants born in Rhode Island, intended primary care provider is collected at time of discharge as part of a developmental risk assessment. That information is sent to KIDSNET but not displayed. KIDSNET will be programmed so that if a child's record is not linked to a primary care provider, the intended provider collected at birth will be displayed on the newborn report screen. We will also explore the possibility of Early Intervention sending the primary care provider to KIDSNET if known.

Goal 2, Objective 2: Add the High Risk NICU Follow-up clinic as a new user to KIDSNET by June 30, 2009

Many of the children needing follow-up from newborn screening as well as many with risk factors for late onset hearing loss are "NICU graduates". High risk NICU patients who have been discharged are seen at the High Risk NICU Follow-up Clinic at Women & Infants' Hospital. The clinic is run by Dr. Betty Vohr, who is also the Medical Director of the Rhode Island Hearing Assessment Program and the American Academy of Pediatrics EHDI State Champion. The NICU Fellows who see the patients are important partners in assuring that newborn hearing screening follow-up is accomplished. The clinic will be given KIDSNET access so that they can check for rescreen and diagnostic results.

Goal 3: Reduce loss to follow-up/documentation

Goal 3, Objective 1: Decrease diagnostic audiology reporting loss to follow-up/documentation to 5% by June 30, 2011

The EHDI program does not have diagnostic information on 12% (17 of 141) infants who did not pass the newborn hearing screen in 2006. Diagnostic audiology reporting is not mandated in Rhode Island. However, there are not a large number of pediatric audiologists and the EHDI program maintains a good working relationship with these critical partners. To update the list of known pediatric audiologists, a survey of the 90 audiologists licensed in the state will be conducted to assess which ones see children, how many, which ages, diagnostic testing method, and equipment used. Those who see children will be offered training on electronic reporting via KIDSNET. This training session will also include a discussion of the importance of reporting all results, including normal hearing, a discussion of laws that permit this reporting and the suggestion of getting parental consent to share the information if desired. In addition, KIDSNET will be upgraded to improve the individualized report audiologists can create for their patients and to create an annual summary report on their patients, as an added incentive to report electronically. A report will be programmed in RITrack to evaluate frequency and volume of reporting in comparison to the survey responses. Outreach will be made to low reporters to try to collect any missing data and to encourage ongoing reporting.

Goal 3, Objective 2: Create secure mechanism to transfer electronic EHDI data among New England States by June 30, 2011

Rhode Island borders both Connecticut and Massachusetts and it is not uncommon for families to cross state lines for health care, including deliveries, primary care and audiology. This creates an additional challenge for collection of EHDI data. The New England States have been working together for several years to review state laws and create agreements allowing sharing of EHDI data under existing state laws. Once those agreements get signed, a secure mechanism to transfer the files electronically will be created. We would like to explore using a web file repository. Using this technology, files or documents are sent, encrypted and deposited onto a server in assigned folders. The folders are password protected so the contents can only be retrieved by authorized users. Upon retrieval, the file is unencrypted. So for example, based on interstate agreements, EHDI staff in each state could simply post a WORD or EXEL document directly to the WFR (it gets encrypted) or run a report that prints out all the data agreed to share with each state. The state specific report or file is deposited on the WFR in an encrypted form in the corresponding state folder. If it is an electronic file, it could be pulled directly into their EHDI data system. A document would just be printed on paper. The idea is to avoid sending data by mail on diskettes, flashdrives, or other less secure methods and to avoid having to re data enter from one system to another.

Goal 3, Objective 3: Improve EHDI Medical Home follow-up capacity by connecting Pediatric Provider Enhancement Program parent consultants to KIDSNET by June 30, 2009

The Pediatric Provider Enhancement Project assigns parent consultants to large primary care offices seeing children with special health care needs. The parent consultants are also parents of children with special health care needs who have personal experience and training with the health care system, Early Intervention, insurance, and the education system. They work with parents of infants and young children to help them navigate these complex systems as well as providing peer support. Many of the children they work with need newborn hearing screening follow-up in addition to many other follow-up activities that also need attention. Access to KIDSNET will allow PPEP parent consultants to check for newborn hearing follow-up needs, newborn blood spot follow-up needs, immunization status, and lead screening status. In this way, they will be able to more comprehensively look at preventive health care needs and facilitate getting it accomplished. PPEP parent consultants will be trained on the EHDI system and KIDSNET and provided with medical home and family friendly algorithms that have been developed to guide families and primary care providers through the EHDI process.

Goal 4: Increase capacity to identify late onset and progressive hearing loss

In addition to Goal 3, Objective 1 (Decrease diagnostic audiology reporting loss to follow-up/documentation to 3% by June 30, 2011), the following objectives apply.

Goal 4, Objective 1: Pilot test collecting school hearing screening data in KIDSNET by June 30, 2011

School hearing screening in grades K-3 is mandated in Rhode Island. The RI School for the Deaf provides the screening. Federal privacy laws (FERPA) prevent sharing those results with primary care providers and others via KIDSNET without parental permission. Audiologists also do not often report diagnostic results back to the school hearing screening program. We propose to pilot test in one or more communities having school nurses collect permission to share school screening results to KIDSNET where it will be available to primary care providers and audiologists. A follow-up plan and related KIDSNET reports will be developed among partners such as primary care providers, parents, school nurses and the School Hearing Screening Program.

Goal 4, Objective 2: Add "reasons for visit" to KIDSNET audiology reporting screen by June 30, 2010

Reasons for visits to audiologists can vary and include but are not limited to failed newborn screen, failed school screen, parental and teacher concerns, primary care referral, Part C referral, and monitoring due to risk factors. Reasons for visit will be added to the KIDSNET audiology reporting screen to start to look at which EHDI partners are instrumental in referring to audiologic evaluation and detection of late onset hearing loss.

3.0 Collaborative Efforts:

The Rhode Island Department of Health is the applicant agency. Within the Department of Health, there are four collaborating programs: KIDSNET, Newborn Screening, Maternal and Child Health (Title V), and Children with Special Health Care Needs. Key collaborators in other organizations include 1) the Rhode Island Hearing Assessment Program at Women & Infants' Hospital; 2) the Department of Human Services Early Intervention; and 3) the Rhode Island School for the Deaf. These are described below. Letters of support are provided in appendix A.

KIDSNET- The KIDSNET program is an integrated child health information system that had included EHDI data since its inception. KIDSNET has an established web-based application that allows authorized sharing of data with state and community partners who help facilitate appropriate preventive health care, including follow-up from newborn hearing screening. KIDSNET will take the lead on the work described in this proposal to build on and enhance the existing capacity for EHDI data collection, tracking and follow-up. KIDSNET is described in detail in section 1.0.

NEWBORN SCREENING PROGRAMS – In addition to newborn hearing screening, the state EHDI coordinator, Kristi Zonno, also coordinates newborn bloodspot and developmental risk screening. The developmental risk screening program is integrated with the electronic birth certificate. This data opens newborn records in KIDSNET and collects demographic data such as race, language spoken in the home, phone number, address, alternate contact information, and primary care provider. This information is key to assuring all infants are screened and receive necessary follow-up. Kristi will work in close collaboration with KIDSNET on all activities of this grant.

MATERNAL AND CHILD HEALTH (TITLE V) – Integration of child health data and connection to medical homes and other community partners via KIDSNET originated in the Title V program. Bill Hollinshead provides leadership and oversight to most public health programs involving women and children, including newborn hearing screening and KIDSNET. A letter of support from Dr. Hollinshead, Title V Director, is included.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS(CSHCN)- The CSHCN Program in Rhode Island does not provide direct services. This program focuses on parent involvement and development of medical homes that can successfully support CSHCN and their families. A recently developed project is the Pediatric Provider Enhancement Project (PPEP). This program places trained parent consultants in pediatric offices with a large number of children with special health care needs. The parents draw on their training and own personal experience to work with families to assure care coordination, peer support, health insurance, and other needs are met. As partners in the medical home, the parent consultants will be given access to EHDI and other data in KIDSNET. They will help assure that newborn hearing screening follow-up and other preventive health needs are accomplished and may be sources of missing EHDI data such as diagnostic audiology results. A letter of support from Deborah Garneau, CSHCN Director, is included.

WOMEN & INFANTS' HOSPITAL, RI HEARING ASSESSMENT PROGRAM (RIHAP) - The Department of Health contracts with Women and Infants' Hospital to coordinate newborn hearing screening and follow-up statewide. They directly carry out newborn hearing screening at Women & Infants' Hospital where more than half of all infants are born in the state and oversee the training, protocols, equipment, data collection and quality assurance at the remaining maternity hospitals in the state. RIHAP is responsible for the EHDI data system (RITRACK) described in section 1.0. The RIHAP Administrator, audiologist, and medical director will all participate in the team working on the proposed activities of this grant. RIHAP also facilitates two important committees that contribute to Rhode Island's EHDI 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 families, audiology, pediatrics, special education, insurance, the deaf community, hospital neonatal nurseries and the Rhode Island Department 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 the Rhode Island Department of 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.

RI DEPARTMENT OF HUMAN SERVICES EARLY INTERVENTION (PART C) – Follow-up from newborn hearing screening cannot be successful without a strong partnership with Early Intervention. In Rhode Island, there is a strong history of collaboration between these programs. Initially both programs were in the same division of the Health Department under the same medical director and program manager. The Part C program was relocated to the Department of Human Services by legislative mandate but the collaborative partnerships remained intact. Both EHDI and Part C exchange data with KIDSNET, making data linkage easier. The Part C program recently hired Julia Lee, a teacher of the deaf, to coordinate services statewide for infants and children with hearing loss and to serve as a single point of entry for referrals. She will be a key participant in strengthening data collection related to Part C and partnering in tracking and assuring services. A letter of support from Brenda Duhamel, the state's Part C coordinator is included.

THE RHODE ISLAND DEPARTMENT OF EDUCATION – RI SCHOOL FOR THE DEAF

The Rhode Island School for the Deaf, under the RI Department of Education, is home to the Family Guidance Program that serves children birth to age three with hearing loss. This program offers 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. The Family Guidance Program contracts with Early Intervention Part C Agencies throughout the state to provide these specialty services. Since the majority of families of children with hearing loss in Rhode Island participate in the Family Guidance Program, this program will link the project to families, as their issues, concerns, and input are crucial to the success of any follow-up effort. Because Family Guidance works closely with families, some of whom are not involved with Part C, they are a potential source of missing diagnostic data.

The School Hearing Screening Program is also run by the RI School for the Deaf. They have partnered in the past with KIDSNET to develop electronic school hearing screening records. Some families whose children fail the school hearing screening take advantage of no cost diagnostic audiology available through an audiologist at the RI School for the Deaf. The next step in this partnership is to collect parental consent to share screening and audiology data with KIDSNET so that primary care providers and school nurses can facilitate appropriate follow-up. This can be an important source of late onset hearing loss data.

RI ACADEMY OF AUDIOLOGY - The RI Academy of Audiology is a profession organization. The majority of audiologists seeing infants and children are members of this group. Winnie

Chung, RIHAP Audiologist, is an active member of the academy and frequently facilitates EHDI activities through the academy.

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 participated in the development of an AAP "pedialink" module for newborn hearing screening and is a member of the Joint Committee on Infant Hearing (JCIH) . Dr. Burke is a pediatrician specializing in caring for children with special health care needs. Both Drs. Vohr and Burke were involved in a 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. They continue to advise and contribute to all our EHDI activities in Rhode Island.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The project team will work cooperatively with the CDC EHDI program to meet the goals of this project and look to them for the support, guidance and technical assistance we have grown to count on. The Rhode Island Department of Health has a long standing relationship with the EHDI team at the CDC. We will also continue to support their needs such as Health People 2010 and other data reporting efforts.

4.0 Program Capacity:

The Rhode Island EHDI System is a well-developed and supported system with considerable experience and expertise providing newborn hearing screening, tracking and follow-up. Rhode Island was one of the first states to mandate and implement universal newborn hearing screening, in part due to advocacy from Dr. Betty Vohr (RIHAP Medical Director and AAP EHDI Champion) and others. That mandate included a fee structure to support the program.

The Department of Health has a history of 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 CSHCN, and Blythe Berger, Ph.D., Chief, Perinatal and Early Childhood Services which includes Newborn Hearing Screening.

In the fifteen years since universal newborn hearing screening began, the EHDI program has developed many collaborative relationships throughout the state including KIDSNET, Early

Intervention Part C, the Family Guidance Program, audiologists and others described previously in section 3.0. The EHDI Program is closely aligned with the newborn bloodspot and developmental risk screening programs which do similar screening and follow-up activities with associated tracking and data needs.

EHDI tracking and surveillance tools have matured during the history of newborn hearing screening in Rhode Island from a stand alone data system collecting relatively few data elements to a sophisticated EHDI data system collecting an abundance of data to meet numerous tracking, surveillance, follow-up and reporting needs. Selected data is integrated with other child health data in KIDSNET to connect with medical homes, Early Intervention, audiologists and others to facilitate collection and appropriate sharing of EHDI data. Mary Catherine Hess, RIHAP Administrator, shared this experience nationally through participation on the CDC EHDI data committee.

5.0 Staffing and Management plan:

The proposed program staff is highly experienced and has participated in the implementation and development of universal newborn hearing screening in Rhode Island since its inception. With close to 15 years of experience screening all newborns for hearing loss, the Rhode Island Department of Health (HEALTH) and it's partners Women and Infants' Hospital, RI Hearing Assessment Program (RIHAP), Department of Human Services Early Intervention Part C Program, and the RI School for the Deaf Family Guidance Program, are well positioned to carry out the objectives described in this application. Key staff is spread throughout the EHDI system bringing multiple perspectives and a long history of collaboration. An organizational chart, job descriptions, and resumes or biographical sketches of key personnel are included in appendices B, C and D respectively.

The proposed Project Director is Ellen Amore, MS. Her educational background is in child development, maternal and child health, and public health. She was the Newborn Screening Manager for seven years during which time she was responsible for newborn hearing screening, developmental risk assessment and blood spot screening and for assuring that records on all newborns were opened in KIDSNET and all infants received each of these important newborn services. Her current position is manager of KIDSNET, which is part of the Data and Evaluation Office that provides support to all maternal and child health programs. This team includes epidemiologists, data and evaluation experts. They will be available to assist with the evaluation portion of this project.

Ariel Lizarda, Newborn Screening data manager, will monitor and track all EHDI electronic file imports into KIDSNET (Vital records, newborn hearing, RITrack), troubleshoot when imports are unsuccessful, resolve errors for all electronic records that did not successfully transfer automatically into KIDSNET, generate and monitor routine and ad hoc data reports from KIDSNET, monitor for and merge duplicate records, and execute KIDSNET EHDI data quality assurance activities. This position will also assist new EHDI related development and testing. The data manager is hired through a contract with VNA of Care New England and activities and oversight are provided by Ellen Amore, KIDSNET Manager.

All activities will be closely coordinated with Kristi Zonno, MS, the state EHDI coordinator. Kristi has a background in genetic counseling. She has worked in the newborn screening programs for three years and has been EHDI coordinator for the past year. She reports to Blythe Berger, Ph.D., who leads the Perinatal and Early Childhood Team. KIDSNET and RITRACK are tools for EHDI tracking and surveillance. As the EHDI Coordinator, it will be Kristi who facilitates the specifications and details for grant related development so that the result will meet the needs of the EHDI program.

The Rhode Island Hearing Assessment Program at Women and Infants' Hospital is another source of key personnel for this project. Betty R.Vohr, M.D., Medical Director, will continue to oversee the Rhode Island Hearing Assessment Program, provide guidance for all newborn hearing screening activities, and advise the grant team through participation in monthly meetings and via email. The RIHAP Administrator position is currently vacant with a search in progress. This is a critical staff position for the project with responsibility for the RITRACK data system, data exchange with KIDSNET, the collection and reporting of all EHDI data, 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. This position is responsible for overseeing all technical development in RITRACK including contract management with the technical vendor, HLN Consulting as well as acting as the program liaison with KIDSNET, and coordinating with KIDSNET data managers to assure that all infants born in Rhode Island have been screened. Although this person will participate in most activities, this position will be specifically responsible for developing hospital screening data reporting and parent notification, electronic production of the national EHDI data report, and creation of a report to evaluate frequency of audiology reporting.

The RIHAP Audiology Coordinator, Winnie Chung, CCC-A, is responsible for supervision of all newborn hearing screening, interpretation of results, and reporting quality indicators. Winnie holds a doctorate in audiology and master's degree in special education and has extensive experience on a cochlear implant team at Kaiser Permanente in California. She will be responsible for surveying audiologists and providing training and feedback to encourage increased reporting of diagnostic results.

Julia Lee is a teacher of the deaf who works for the Early Intervention Program under contract with Family Services. She serves as a single point of entry for referrals of infants and children with hearing loss and assures appropriate follow-up and services are rendered. She will participate in the design and testing of modifications to KIDSNET that will improve capacity to track service access. She will also be part of the team to develop and implement a protocol to monitor progress of each infant with failed newborn hearing screen through the EHDI system.

Lena Green is director of the Family Guidance Program at the RI School for the Deaf. Lena will serve as facilitator of activities related to Family Guidance including reporting participation in Family Guidance via KIDSNET. She will also be part of the team to develop and implement a protocol to monitor progress of each infant with failed newborn hearing screen through the EHDI system.

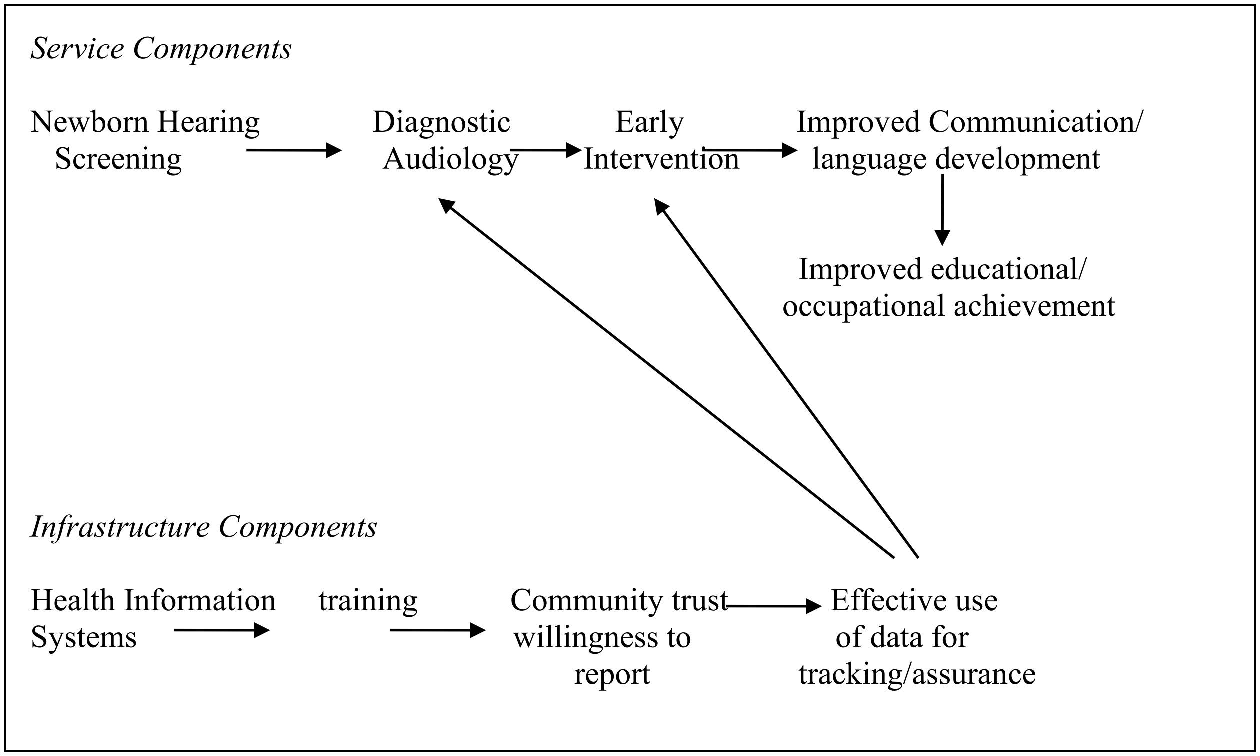
HLN Consulting will be the technical consultant for the project. HLN brings an unusual combination of public health, technical and health information technology expertise. Since its inception, HLN has directed its health information technology efforts in the design, development and use of specialized healthcare applications in core areas of public health, including integrated child health systems, immunization information systems, data exchange, RHIO planning and tele-health. HLN has worked for several states on similar public health information technology projects and participates in many related national committees and workgroups. As a result, they are able to provide in-depth subject matter expertise and leverage their affiliations to contribute to the conceptualization of emerging issues and produce high-quality technology solutions. HLN has an in depth knowledge of RITRACK, having recently upgraded it to its current state.

Furthermore, KIDSNET is a complex system and database and HLN has over 5 years of experience working in this complex environment and linking EHDI data from RITRACK.

6.0 Evaluation Plan:

The Rhode Island Infant Hearing Screening Advisory Committee, the Rhode Island Infant Hearing Screening Follow-Up Committee, and the KIDSNET Stakeholders Group are important stakeholders that follow the development and evaluation of the EHDI system, including its information systems. These groups have membership that can be actively engaged in many of the evaluation efforts.

To set the stage for evaluation, the following logic model relates to activities in this application.



The long term health outcomes of improved language, communication and educational and occupational achievement are beyond the scope of the three year grant period. The goals and objectives of this application primarily focus on enhancing the EHDI health information system infrastructure, improving capacity and willingness to report to that information system, and using that information to improve timely completion of diagnostic audiology (by three months of age) and intervention (by six months of age).

Improvements to the EHDI information system infrastructure proposed in this application include:

Goal 1, Objective 1: Development of electronic hospital screening data and parent notification and rescreen or audiology appointment scheduled prior to hospital discharge

Goal 1, Objective 2: Develop capacity to capture data on Family Guidance Program participation in KIDSNET and explore ways to collect data related to other services provided both from Part C and "non-Part C", such as speech language pathology, and outcomes, such as language skills.

Goal 1, Objective 3: Develop automated annual national EHDI data report

Goal 2, Objective 1: Make intended primary care provider available to EHDI partners through KIDSNET

Goal 3, Objective 2: Create secure mechanism to transfer electronic EHDI data among New England States

Goal 4, Objective 1: Pilot test collecting school hearing screening data in KIDSNET

Goal 4, Objective 2: Add "reasons for visit" to KIDSNET audiology reporting screen

Evaluation: The above enhancements to RITRACK and KIDSNET will be monitored and evaluated using process evaluation milestones. These include completion of 1) programming specifications, 2) programming, 3) testing, 4) implementation in production environment.

Goals and objectives focusing on training include:

Goal 2, Objective 2: Add the High Risk NICU Follow-up clinic as a new user to KIDSNET

Goal 3, Objective 1: Decrease diagnostic audiology reporting loss to follow-up/documentation to 5% using training on electronic reporting in KIDSNET

Goal 3, Objective 3: Improve EHDI Medical Home follow-up capacity by connecting Pediatric Provider Enhancement Program parent consultants to KIDSNET

Evaluation: Process measures to evaluate these activities include completion of training plans and numbers of audiologists and parent consultants trained. The number and percent of trained NICU staff, audiologists and parent consultants using KIDSNET will also be monitored over time.

Acceptability of a surveillance system is an important attribute to evaluate and is reflected by a sense of trust and willingness on the part of the community to report data. Goals and objectives aimed at building community trust and willingness to report include:

Goal 1, Objective 4: Develop and implement an EHDI data feedback plan

Goal 3, Objective 1: Decrease diagnostic audiology reporting loss to follow-up/documentation to 5% - improve the individualized report audiologists can create for their patients and to create an annual summary report on their patients, as an added incentive to report electronically

Goal 3, Objective 2: Create secure mechanism to transfer electronic EHDI data among New England States

Goal 4, Objective 1: Pilot test collecting school hearing screening data in KIDSNET

Evaluation: System use and reporting is critical to the success of the information system. It is possible to monitor use of KIDSNET by user group (audiologists, early intervention, etc) and to monitor the number and % of audiologists reporting electronically as an indicator of willingness to report. Use of the interstate web-file repository will also be tracked across time once it is in place.

Goals and objectives aimed at effective use of data for tracking and assurance are:

Goal 1, Objective 2: Develop reports to monitor status of each infant who did not pass the newborn hearing screen to be used to seek out missing diagnostic data and assure participation in Early Intervention and Family Guidance when appropriate.

Goal 2, Objective 1: Make intended primary care provider available to EHDI partners through KIDSNET

Goal 3, Objective 1: Decrease diagnostic audiology reporting loss to follow-up/documentation to 5% - Report programmed in RITrack to evaluate frequency and volume of reporting with outreach to low reporters

Goal 4, Objective 2: Add "reasons for visit" to KIDSNET audiology reporting screen –use report to understand which EHDI partners are instrumental in referring to audiologic evaluation and detection of late onset hearing loss.

These objectives are intended to impact the service outcome measures of screening by 1 month of age, diagnosis by 3 months of age, and intervention by 6 months of age. Measuring these basic indicators expected of all EHDI programs are good indicators of the success of these activities. In addition, these objectives are aimed at reducing the % lost to follow-up or documentation of diagnostic audiology and intervention so those rates will be followed as well.