

PROJECT NARRATIVE

RHODE ISLAND DEPARTMENT OF HEALTH
EARLY HEARING DETECTION AND INTERVENTION PROGRAM

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INTRODUCTION

Rhode Island (RI) has a longstanding commitment to ensuring that hearing loss in newborns is detected and treated at the earliest possible point. Early detection with appropriate and timely follow-up is the best way to ensure that children with hearing loss have the opportunity to reach their full potential. The RI Department of Health (RIDOH) has worked for decades to develop and maintain a high-quality system of newborn hearing screening and follow-up based on the understanding that early support for children and their families plays a significant role in mitigating negative outcomes that can be associated with hearing loss.

Since RI passed universal newborn hearing screening legislation in the early 1990s, it has maintained consistently high screening rates. Contributing to RI's high rate of screening is the fact that newborn hearing screening is a covered benefit reimbursable by all health insurers, and RI has high rates of infants who are insured at birth.ⁱ Follow-up has always been an essential component of RI's Early Hearing Detection and Intervention (RI-EHDI) program. Between 2013 and 2016, hearing screening and follow-up, supported by the Health Resources and Services Administration (HRSA) funds, focused on reducing the number of children lost to follow-up after failure to pass a newborn hearing screen. RI implemented programmatic changes and quality improvement activities to support the RI-EHDI program to reach the Joint Committee on Infant Hearing (JCIH) targets of: hearing screening by 1 month of age, audiological evaluation by 3 months of age, and intervention by 6 months of age.ⁱⁱ

RI maintains high rates of overall newborn hearing screening. In 2017, there were 11,199 infants born; 99.1% or 11,102 of them received a newborn hearing screen. However, RI has work to do to meet the 1-month recommendation, as only 94% of infants were screened by 1 month of age. In addition, RI needs to improve on the 3-month recommendation. In 2017, only 59.2% of infants received audiological evaluation by 3 months of age, leaving over 40% of infants not receiving audiological evaluation at the earliest possible point and potentially delaying their entry into needed intervention services. Finally, RI also needs to make improvements in its EHDI system to ensure that children who have a confirmed hearing loss are enrolled in Early Intervention (EI) and other appropriate services, with documentation of enrollment, by six months of age. In 2017, only 40% of children with a documented hearing loss had documentation that they were enrolled in EI by 6 months of age. This means that these children were not enrolled in services that would support their speech and language development and are at potential risk for academic failure. Improving timely enrollment is a high priority for the RI-EHDI program. RI looks forward to this opportunity to focus work on systems development and activities that support and complement early detection of hearing loss and appropriate intervention, including working with health care professionals and families in learning communities, strengthening relationships with EI and fostering a strong family role within the RI-EHDI system.

RI-EHDI is a collaborative effort by design; current partners include Maternal and Child Health programs such Children with Special Health Care Needs (CSHCN), Home Visiting, Newborn Developmental and Bloodspot Screening, and the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) programs at the Rhode Island Department of Health. Other partners include the Commission for the Deaf and Hard of Hearing, birthing hospitals, primary care and specialty providers, audiologists, the Part C EI Programs, RI School for the Deaf, otolaryngologists, geneticists, parent consultants, and families. These key partners collaborate with RIDOH to develop hearing screening systems, programs, and tools for follow-up, intervention, quality assurance, and evaluation to ensure successful outcomes for children

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and families who are involved in the RI-EHDI program.

The RI-EHDI program is integrated into the state's system of early childhood services; this has ensured that the program is coordinated at the state and community level with other early childhood systems and supported RI to have high rates of follow-up for children who failed a newborn hearing screen. However, due to recent challenges such as reduced capacity of audiologists, changes in hospital procedures and insurance co-pays and deductibles, and expanding income disparities in the state, RI is seeing a greater need to support families of newborns and infants who do not pass a newborn hearing screen to access appropriate evaluation and intervention follow-up at the earliest possible point, consistent with the JCIH 1:3:6 guidelines.

The overarching goal of RI's proposed project is to sustain a comprehensive, coordinated, statewide EDHI system of care and services that ensures newborns and infants throughout RI receive, and remain engaged in, appropriate and timely services which include screening, diagnosis, and early intervention. This purpose aligns with the 2017 EDHI Act, that ensures every newborn infant in Rhode Island is screened and evaluated, through the authority of Rhode Island's General Laws, Section 23-13-13. Goals of this project will be accomplished by the following: 1) Engaging all EHDI system stakeholders to improve developmental outcomes of children who are deaf or hard of hearing (D/HH); 2) Ensuring that newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI by 6 months of age while reducing lost to follow-up/lost to documentation rates; 3) Identifying ways to expand state capacity to support hearing screening in young children up to 3 years of age; 4) Strengthening capacity to provide family support and engage families with children who are D/HH and adults who are D/HH throughout the EHDI system; 5) Engaging, educating, and training health professionals and service providers in the EHDI system about the 1-3-6 recommendations; and lastly 6) Facilitating improved coordination of care and services for children who are D/HH and their families. This project will strengthen and sustain the RI-EHDI system in Rhode Island and foster a supportive, comprehensive and coordinated EHDI systems of care for all families with newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing (D/HH).

NEEDS ASSESSMENT:

Overview

RI is a small, largely urban state with a total population of slightly over 1 million (1,057,315). In 2016, according to the American Community Survey, there were 208,640 children under 18 years of age, representing 20% of RI's population. Just over a quarter (26%) of the child population was under five years of age.ⁱⁱⁱ Similar to the rest of the nation, the birth rates in RI have been dropping in recent years. In 2017, 11,119 infants were born in RI; this is a slight decline from 2016, in which 11,430 infants were born. Rhode Island is divided into 39 cities and towns that each govern primary and secondary education, subdivision of land and zoning, and housing code enforcement in their local community.

Much of the state's population (636,084) is concentrated in the central part of the state, which has the largest and most populated cities. The seven largest cities with the greatest density of population are Providence, the largest city and RI's capital, Pawtucket, Central Falls, East Providence, Cranston, Warwick, and West Warwick. The combined population in this urban area is 480,281, 45% of the total population in the state. These densely populated cities in the center

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of the state are more ethnically and culturally diverse than other areas of RI. The greatest concentration of healthcare providers and social service providers is also in this central area of the state. For example, there are 335 pediatricians in RI statewide and nearly 70% (231) are located in these cities. There are 13 pediatric audiologists in RI, and 8 practice in one of these cities, leaving five pediatric audiologists to cover the remainder of the state. In addition, there are only two sites in the state that can perform the Auditory Brainstem Response test; both of these are in Providence meaning there is limited accessibility for those that live in more distant geographic areas. There is only one audiologist in RI that speaks Spanish; she works at the Rhode Island School for the Deaf, located in Providence. The concentration of service providers in the central area of the state may present challenges for families who don't have transportation, or for families who would be facing long distances to access services for their very young children.

Rhode Island has 5 birthing hospitals in a geographically small state, which facilitates maintaining high newborn screening rates. In 2017, the large majority of the births (79%) occurred at Women & Infants Hospital, RI's regional perinatal tertiary care center, located in Providence. About 7% of the births occurred at Kent, a hospital in the central part of the state, and about 3% of the births occurred at Landmark, the hospital in the northern community of Woonsocket. In addition, 6% percent of births took place at South County Hospital, located in the southern section of the state, and 4% occurred at Newport Hospital, located in the East Bay.^{iv} The small number of birthing hospitals, in a geographically small state, facilitates maintaining high newborn screening rates. However, RI has significant work to do to increase the number of infants, who complete the screening process within 1 month and who after failing the initial hearing screen, have an audiological evaluation by 3 months of age. RI also needs to focus on increasing the number of infants, who are diagnosed as deaf or hard of hearing and are enrolled in EI by 6 months of age.

Leadership for the Newborn Hearing Screening program (NBHS), is based at the Rhode Island Department of Health, in the Division of Community, Family Health and Equity. Screening, follow-up, tracking, and data management are coordinated through a contract with the Rhode Island Early Hearing Detection and Intervention Program (RIEHDI) located at Women and Infants Hospital in Providence.

The primary target population for this grant is newborns and infants (and their families) who were identified as deaf or hard of hearing through diagnostic evaluation subsequent to a failed universal newborn hearing screen. To ensure that RI is able to meet the program objectives, RIEHDI must comprehensively examine its system of services for those infants that did not receive services consistent with the time frames outlined in the JCIH 2007 position statement. This includes infants who are not screened by one month of age, infants who do not receive an audiological evaluation by three months of age, and infants who are not referred or do not enroll in EI by six months of age, as well as those infants who are lost-to-follow up (LTF), that RIEHDI has not been able to engage in either screening, evaluation or intervention. By understanding the needs of these children and their families and the barriers that they may face to engaging in services, RI can develop and support a comprehensive EHD system of services.

This needs assessment is based on the population of children born in 2017. In 2017, there were 11,199 infants born; 99.1% or 11,102, of them eventually received a newborn hearing screen. Of the 97 children who were not screened, 60 died, 12 had parents who refused, and 25 were lost to follow-up/lost to documentation (LTF/LTD). Of the 25 children who were LTF/LTD, 8 were transferred out of state; of these 8 children, 6 of them have received follow-up.

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There were 7 children born at home, who were LTF/LTD; 3 of these children eventually received follow-up or refused the newborn screen.

In 2017, the 1-month screening rate was 94.3%; there were 629 infants who did not complete their screening by 1 month of age. All of these children received an initial hearing screen by 1-month of age, however, because they failed their initial screen, in order to meet the 1-month guideline, they needed a re-screen prior to reaching 1 month of age, which did not occur.

As with the 1-month screening rate, RI needs to improve on the state's 3-month diagnosis rate. In 2017, there were 384 infants who completed and failed their initial screen; 138, or 36%, were diagnosed by 3 months of age. Another 12% were diagnosed between 3 and 6 months of age, and 13% were diagnosed after 6 months of age. However, 39% do not have a diagnosis or have an undetermined diagnosis. Over half of the children who do not yet have a diagnosis have been contacted but are unresponsive.

RI's rate of enrollment into EI by 6 months of age is lower than the target. In 2017, of the 35 infants with confirmed hearing loss, 14, or 40%, were enrolled in EI before they reached 6 months of age, 6 of the 35 infants (17%) were enrolled between 6 and 12 months, 8 (23%) were enrolled after 12 months, and 7 (20%) were not enrolled. Of these 7 infants who were not enrolled, 2 parents refused, 1 parent could not be contacted, 2 were contacted but unresponsive, 1 moved out of RI, and 1 was a non-resident.

The state's hearing data from the 2017 CDC (Centers for Disease Control and Prevention) EHDI Hearing Screening and Follow-up Survey (HSFS) report, provides information on how infants in RI are tracked through newborn hearing screening, audiological evaluation and intervention.

Needs of the population & barriers

In 2017, the 1-month screening rate was 94.3%; there were 629 infants who did not complete their screening by 1 month of age. All of these children received an initial hearing screen by 1 month of age, however, because they failed their initial screen, in order to meet the 1-month guideline, they needed a re-screen prior to reaching 1 month of age. The majority (91%) of the 629 babies completed their rescreen before 3 months of age. Barriers to reaching the 1-month guideline include need for an outpatient rescreen and NICU status. The strategies for addressing these barriers will be explored in the Methodology Section.

As with the 1-month screening rate, RI needs to improve on the state's 3-month diagnosis rate. In 2017, there were 384 infants who completed and failed their initial screen; 138, or 36%, of the infants were diagnosed by 3 months of age. Of the 384 infants, 119 passed their AABR within 3 months and were diagnosed with normal hearing in both ears. The additional 19 infants were diagnosed with hearing loss within 3 months of age. In 2017, there were 246 infants who did not have a diagnosis within 3 months of age. Some of these infants (95) were diagnosed after 3 months of age: 79 infants were diagnosed with normal hearing in both ears and 16 infants were diagnosed with a confirmed hearing loss after 3 months of age. However, there were 151 infants who did not have documented diagnosis: 11 are still awaiting a final diagnosis (as of April 2019, they had seen an audiologist at least once in the last 6 months), 84 were contacted but were unresponsive, 15 could not be reached, 13 moved out of state, 9 refused services, and 1 was medically fragile. In addition, 18 children had been seen for at least one evaluation but had not had a diagnostic evaluation in the past 6 months.

There are multiple barriers to diagnosis by 3 months of age. These include: a) timeliness

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of screens b) a high refer rate for diagnostic appointments; c) diagnostic center location/availability; d) the follow-up system at diagnostic centers; e) the time it can take to diagnose infants; f) audiologists' reluctance to diagnose. The strategies for addressing the barriers to diagnosis are addressed in the Methodology Section.

Finally, in 2017, there were 35 children diagnosed with hearing loss: 14 (40%) were enrolled in EI by 6 months of age, 6 (17%) were enrolled between 6 and 12 months, 8 were enrolled after 12 months, and 7 were not enrolled in EI. Of the families that did not enroll in EI, 1 could not be contacted, 2 refused intervention services, 2 were contacted but unresponsive, and 2 live out of state. All RI infants diagnosed with hearing loss are eligible for EI services. Per the Joint Committee on Infant Hearing (JCIH) recommendations, all infants with hearing loss should be enrolled by 6 months of age. There are multiple barriers to enrollment in EI by 6 months of age. When there is a delay in evaluation, some children do not have hearing loss as a single established condition by 6 months of age; therefore, they are not eligible for EI. Other factors that contribute to a delayed EI enrollment include a refusal of EI service, delays due to denial of the hearing loss diagnosis, and lastly an infant's degree of hearing loss. Strategies for addressing these barriers are outlined in detail in the Methodology section.

Disparities

At the present time RI has data on many factors that can lead to disparities, including race and ethnicity, geography, socioeconomic status, disability status, language, and other factors. The state does not routinely collect data on gender identity, sexual orientation, or health literacy. RI is fortunate to have KIDSNET, which tracks information on families' race, ethnicity, socio-economic status, primary language, and other useful information such as mother's age at time of child's birth and her education level. These data can be used to determine if there are disparities between the babies who were lost to follow-up and those who were diagnosed with hearing loss or found to have normal hearing. The RIDOH has 3 leading priorities, which include 1) addressing the socioeconomic and environmental determinants of health; 2) eliminating health disparities and promoting health equity; 3) ensuring access to quality health services for all Rhode Islanders, including the state's vulnerable populations. It is important for the RI EHDI program to know if there are disparities, particularly with those families that did not receive a diagnosis.

It can be helpful to look at characteristics of those families who were lost to follow-up between a failed hearing screen and a diagnostic assessment to determine if there are disparities between the families and the overall population. In 2017, there were 151 children who did not pass their hearing screens and never received a diagnosis. In comparing those children who never received a diagnosis with the population of babies who were born in RI in 2017, there are clear differences in socioeconomic status and maternal differences. For instance, of all of the RI-based mothers who delivered babies in 2017, 47% of them were on public insurance, 10% did not complete high school, 41% were single, and 89% spoke English as their primary language. In comparison, the families in the LTF group were, in greater proportion on public insurance (68%), and a greater percentage of the mothers did not complete high school (at least 21%). In addition, more mothers, in the LTF group listed Spanish as their primary language. The limited language capacity of the audiology community may impact the ability of these families to get necessary diagnostic services and follow-up.

Similarly, the racial breakdown of those families who were LTF are also different. Sixty-three percent of all RI-based mothers who delivered in 2017 identified as white, 7% identified as

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black, and 1% identified as American-Indian. However, of those families who were LTF, 52% identified as white, 11% identified as black, and 4% identified as American-Indian.

There are also differences between the overall population of babies born to RI families and those with hearing loss. There are slightly more mothers who identify as black or American Indian who have babies diagnosed with hearing loss versus the population as a whole. In addition, there are more Portuguese-speaking mothers who had babies with hearing loss. A higher proportion of those mothers whose babies were diagnosed with hearing loss did not complete high school and were also single.

Another trend in RI is the number of Spanish speaking families not engaged in EI services. In 2017, out of 7 Hispanic families, only 3 infants enrolled in EI services. Professionals working with deaf and hard-of-hearing individuals would benefit from a deeper understanding of this population, because the percentage of deaf and hard-of-hearing children in the Hispanic population is increasing.^v

Best practice guidelines for working with children who are D/HH indicate the importance of providing services that are family-centered and culturally sensitive^{vi} to support family engagement in all aspects of service delivery. Language barriers and cultural differences between the provider and patient can compromise patient satisfaction, and possibly treatment outcomes, if patients feel their needs are not being addressed in a manner that acknowledges their cultural perspective.^{vii} Barriers to accessing services for many of these families may include difficulty finding a service provider that speaks their language or who provides culturally appropriate services. It is important that the information provided to families is of the same quality and quantity provided to native English speakers and that it is delivered in a manner that is accessible to the families. Even when culturally diverse families are able to communicate successfully in spoken English or ASL, they may have values and beliefs that affect their understanding and acceptance of information conveyed and their willingness to follow through on recommendations. Therefore, it is essential that the manner in which information is delivered is respectful of the beliefs and values of the families and their countries of origin. Family engagement and system leadership provides a unique perspective to the EHDI program. It also creates greater understanding and knowledge of challenges and opportunities families are faced with. Family engagement is no longer just an idea it is active participation and involvement by parents of the target population. In order to ensure that effective parent engagement occurs, RI-EHDI needs to consider that for many families, money, time, travel, parking, childcare can all be “real” barriers for parents to participate in things. Families are a crucial partner when it comes to decision making for their child’s health outcome. RI-EHDI must honor family decisions about what is best for their own child and family. Families also provide an important role when it comes to “diverse perspectives”, they can offer their expertise to guide EHDI practices and policies, resulting in more family-centered EHDI system.

Barriers in service areas

The concentration of service providers in the center of RI has 2 significant implications for RI-EHDI. The first implication is that the concentration of audiology providers in the center of the state should ensure that services are accessible to families in these areas. However, within this large central area of the state are Providence, Pawtucket, and Central Falls, 3 of the 4 cities that make up RI’s “core cities.” According to the RI KIDCOUNT 2019 Factbook, core cities are those in which the “highest percentage of children live in poverty.” There is one additional core city, Woonsocket, which is in the northern part of RI. In addition to high rates of poverty, these

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cities also have greater proportions of children living in families who have other risk factors for poor outcomes, including high numbers of parents who are single and did not finish high school. Core cities also have a large proportion of families who speak a language other than English.^{viii} Barriers to accessing services for many of these families may include difficulty finding a service provider that speaks their language or who provides culturally appropriate services. There is a need for audiology services to be provided in languages other than English, since there is a proportion of families who report a language other than English as their primary language and who have children who are D/HH. Although this may be a small number of children, if they cannot access the necessary services, they may experience developmental and language delays. In addition, young parents, particularly those experiencing mental health problems, may feel overwhelmed by having to negotiate complicated service systems without adequate support. It may be challenging for a family to find transportation, particularly if a family has multiple young children.

The second implication to the concentration of service providers in central RI is that necessary audiology and follow-up services may be challenging to access in the Southern and Northern ends of the state. Families that live in these areas may be required to travel to get the services that their child needs. They may encounter transportation barriers, because the state's public bus system is inadequate in these areas. Audiological services are a bit less challenging to access in the East Bay region of RI where there are several audiologists; this area is in close proximity to southeastern Massachusetts, which also has accessible audiology provider.

METHODOLOGY

The overarching goal of this project is to support the development of statewide programs and systems of care that ensure that children who are deaf or hard of hearing are identified through newborn, infant, and early childhood screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development. RI will accomplish this goal by focusing efforts on: 1) engaging all EHDI system stakeholders at the state level to improve developmental outcomes of children who are D/HH; 2) ensuring that all newborns meet the 1-3-6 recommendations and that few children are lost to follow-up/documentation; 3) expanding state capacity to support hearing screening in young children up to 3 years of age; 4) improving family engagement, partnership, and leadership within the EHDI programs and systems; 5) increasing health professionals' knowledge of the 1-3-6 recommendations and the EHDI system; 6) facilitating improved coordination of care and services for children who are D/HH and their families.

RI's specific targets that will be achieved through the methods proposed below are:

- By March 31, 2021, to complete a newborn hearing screen on 95% of the infants by 1 month of age. Between March 31, 2021 and March 31, 2024 to increase this rate by 1% each year.
- By March 31, 2024
 - To achieve a minimum rate of 85%, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.
 - To achieve a minimum rate of 80%, the number of infants identified to be D/HH that are enrolled in Early Intervention services no later than 6 months of age.
 - To increase by 20% from baseline, using data collected from year 1 as baseline data, the number of families enrolled in family-to-family support services by no later than 6 months of age.

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- To increase by 10% from baseline, using data collected from year 1 as baseline data, the number of families enrolled in D/HH adult-to-family support services by no later than 9 months of age.
- To increase by 10% from baseline, using data collected from year 1 as baseline data, the number of health professionals and service providers trained on key aspects of the EHDI program.

Rhode Island has demonstrated a commitment to newborn hearing screening and follow-up and has achieved almost 100% of infants screened for hearing loss annually for more than several years and a comprehensive follow-up system that ensures infants and their families do not become lost to follow-up or lost to documentation.

Proven strategies carried out from previous project periods will position the RI-EHDI program to focus on the overarching goal of this funding opportunity: to support Rhode Island's systems of care to ensure that children who are D/HH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development. These strategies include infants who are not screened by one month of age, infants who do not receive an audiological evaluation by three months of age, and infants who are not referred or do not enroll in Early Intervention by six months of age, as well as those infants who are lost-to-follow up, that RI-EHDI has not been able to engage in either screening, evaluation or intervention.

The Rhode Island Newborn Hearing Screening Program is committed to evaluating the effectiveness of our RI-EHDI program, which the program will do through an assessment of the timeliness of screening, diagnostic follow up, and referral to Early Intervention services. The following methods to address the goals and objectives were developed with input from a variety of stakeholders including the RI EHDI Advisory Committee, EI providers, families, the RI-EHDI CQI team, and community service providers.

Goal 1: Engage and coordinate all stakeholders in the state EHDI system to meet outcomes goals of the program

Objective 1.1 Strengthen the current RI-EHDI infrastructure to ensure all newborns receive hearing screening by 1 month of age, confirm diagnosis by 3 months of age, and for those infants who are D/HH enroll in early intervention by 6 months of age.

For the benefits of universal newborn hearing screening to be fully realized, screening must be appropriately coordinated and linked with diagnostic and early intervention services and the child's medical home in a way that is family-centered and culturally competent. Procedures for evaluating newborn infants for hearing loss have been developed to support birthing facilities throughout the state. Additionally, RI-EHDI maintains Memoranda of Agreement that set forth policies and procedures regarding NBHS as well as technical support responsibilities, timeliness of data reporting, and hearing screening personnel requirements.

Ensure all newborns receive hearing screening by 1 month of age

During this grant period, RI will strengthen the current RI-EHDI infrastructure to ensure that all newborns have completed their newborn hearing screen by 1 month of age. This will be done by focusing on a) training; b) monitoring the rate of missed screens and rate of referral for rescreen; c) NICU policies.

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The RI-EHDI program trains all individuals, who conduct newborn hearing screening, on protocols and equipment. Screeners receive a competency checklist and are required to watch the National Center for Hearing Assessment and Management (NCHAM) newborn hearing screening training video. In 2015, the state EHDI program transitioned all birthing hospitals to electronic reporting of all hearing screening results. To ensure timely electronic data transfers from all birthing hospital, the EHDI Audiology Coordinator trains, on a regular basis, all birthing facilities on the electronic data transfer protocol. In addition, the EHDI Audiology Coordinator and the EHDI Follow-up Coordinator use the data that is transferred to monitor missed screens and high refer rates. As soon as they notice issues, they provide technical assistance. To address the loss to follow-up rate after an initial newborn hearing screening, the EHDI program provides all birthing hospitals with practice profile reports during annual hospital site visits. Feedback is provided directly to the program nurse manager at each birthing hospital to address any areas of concern from data review.

In 2017, one of the barriers for meeting the 1-month screening requirement was related to the hospitals' use of new equipment. In 2016, all of the birthing hospitals began screening using new equipment; in 2017, this resulted in a higher refer rate for a rescreen. As the screening staff has become more comfortable with the new equipment, the need for a rescreen has decreased. However, even though the need for rescreens has decreased since 2017, some infants will fail their hospital-based screen and will need to return to the birthing hospital for a rescreen after the infant has been discharged. The family, who has a newborn, must travel within a specific period of time to get a rescreen. It can be challenging to get out of the house with a newborn, particularly if a family does not have access to reliable transportation. This challenge is compounded in the winter months when a family must contend with inclement weather.

During the grant period, the EHDI Program will explore whether all hospitals are typically scheduling families within 1 month, how often families are missing their appointments and able to reschedule them, and the system of reminders. EHDI staff will work with the birthing hospital staff to better understand their procedures and to determine what changes might need to be made to improve the 1-month screening rate. Along with strengthening the process at the birthing hospitals, the RI-EHDI team will work with primary care providers to ensure that they are also helping to ensure that the screen is completed by 1 month of age.

In addition, Neonatal Intensive Care Unit (NICU) babies affect the 1-month screening rate. Screeners must wait to screen babies until they are 34 weeks old. Many infants in the NICU are not eligible for a screen due to a medical condition and screeners will not screen babies if they are on oxygen. In some cases, the screening staff do not know when a baby, who is in the NICU, is eligible to complete his/her hearing screen. Often babies are eligible within the 1-month guideline, but screening staff are not told that they are eligible until right before discharge, causing the infant to miss the 1-month goal. In other cases, infants are missed because they are discharged or transferred before the screeners are notified. RI-EHDI will investigate QI activities with the regional tertiary care facility to increase/improve the rate of initial hearing screening in the NICU.

Data are provided regularly to the State EHDI Advisory Committee for Newborn Hearing Screening and the state's Newborn Screening task force are informed regularly, regarding EHDI benchmarks 1, 3, and 6. Presenting this data allows EHDI stakeholders and parents of infants who are deaf or hard of hearing with the opportunity to provide their input regarding any current systems issues and/or barriers families may be facing.

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Confirm diagnosis by 3 months of age

As noted in the Needs Assessment, a large proportion of children who completed and failed their initial screen were not diagnosed by 3 months of age. Data from 2017 indicate that only 59.2% of children who failed their initial screen were diagnosed by 3 months of age. As mentioned in the needs assessment, the RI-EHDI program has determined that the following factors contribute to delayed diagnoses: a) a delay in screening, which then further affects the age at which they are diagnosed; b) a high refer rate for diagnostic appointments; c) diagnostic center location/availability; d) the follow-up system at diagnostic centers; 3) the time it takes to diagnose infant; f) audiologists' reluctance to diagnose.

In 2017, there were a large number of infants who failed their initial inpatient screens at the hospital and needed an outpatient rescreen. Many of these rescreens did not occur within 1 month of age. If a screening happens after 1 month of age, it is even more challenging to get a child diagnosed by 3 months of age. In RI, the initial screening at the hospital, is performed using Otoacoustic Emissions (OAE) test. If the infant fails this initial screen, (s)he is then subsequently tested, in the hospital, using the Automated Auditory Brainstem Response (AABR) test. If the infant fails the AABR test, she is scheduled to return to the hospital for an outpatient rescreen. For most of 2017, infants were rescreened on an outpatient basis using the AABR. This resulted in a high refer rate for diagnostic assessments. In November 2017, the RI-EHDI program changed the rescreen test, so that it was performed using OAE. This is a quicker, more effective test that results in a much lower refer rate. However, because the change did not occur until late in 2016, there were a large number of infants who were referred for a diagnostic appointment.

Diagnostic center availability can affect whether children are diagnosed by 3 months of age. In RI, the family chooses if they'd prefer to have the diagnostic appointment at Hasbro or Women & Infants (W&I). Both of these diagnostic centers are located in Providence. If a family chooses to complete the diagnostic appointment at Hasbro, the child's pediatrician must complete a referral to Hasbro; this can result in a delay in timeliness of completing a diagnostic appointment. If the child is rescreened at W&I and chooses to have a diagnostic appointment at W&I, hospital staff automatically schedule the appointment. However, if a child is rescreened at another hospital, the staff from those hospitals must call Women & Infants; if the scheduler is available, she schedules the appointment and the family walks out of the rescreen with their scheduled diagnostic appointment. When the scheduler is not available, the hospital screening staff must fax a referral form to W&I, and the scheduler calls the family at a later point. The RI-EHDI program will explore whether the need for a referral for a diagnostic appointment causes a delay in completion.

Diagnostic appointments that are missed often lead to a child being diagnosed after three months of age or not at all. When a family misses their initial diagnostic appointment, a RI-EHDI staff member contacts the family to reschedule them or to offer additional options. Many infants require more than one diagnostic appointment to receive a diagnosis. Once a family has been seen by an audiologist, the diagnostic center, as opposed to the EHDI program, becomes responsible for tracking the child. In order to assist diagnostic centers with scheduling and tracking evaluations, RI-EHDI will review, with the two main diagnostic centers, the policies and protocols for families who do not keep appointments and determine if additional work, such as a continuous quality improvement project, must be done as well.

For those children who do receive a diagnostic evaluation, many will receive a diagnosis, such as conductive hearing loss, that may require medical management. The transient nature of

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conductive hearing loss often prevents a confirmed diagnosis of permanent hearing loss or normal hearing by 3 months of age. It has also been proven to be difficult to continue to engage families in keeping appointments and managing the medical aspect of conductive hearing loss. The RI-EHDI program will look at the practices of other states to determine if any other programs have had more success with retaining families who have a child with conductive hearing loss.

Furthermore, some audiologists are reluctant to diagnose a child. However, to bill for services, audiologists must provide a Hearing Loss diagnosis. Currently, audiologists do not enter the International Classification of Diseases (ICD-10) code into KIDSNET. Therefore, the EHDI program is working on changing the page in KIDSNET to include the ICD-10 code. In addition, the EHDI team is also working on a project to try to extract data directly from the electronic medical records used at Women and Infants and Hasbro Hospitals.

Ensure EI enrollment by 6 months of age:

In 2017, there were 35 children diagnosed with hearing loss: 14 (40%) were enrolled in EI by 6 months of age, 6 (17%) were enrolled between 6 and 12 months, 8 were enrolled after 12 months, and 7 were not enrolled in EI. Of the families that did not enroll in EI, 1 could not be contacted, 2 refused intervention services, 2 were contacted but unresponsive, and 2 live out of state. All RI infants diagnosed with hearing loss are eligible for EI services. Per the Joint Committee on Infant Hearing (JCIH) recommendations, all infants with hearing loss should be enrolled by 6 months of age. There are multiple barriers to enrollment in EI by 6 months of age.

One major barrier is that, when there is a delay in evaluation, some children do not have hearing loss as a single established condition by 6 months of age; therefore, they are not eligible for EI. To reduce the timeframe of enrollment into EI for children without a permanent hearing loss diagnosis, RI-EHDI will work with EI to explore the possibility of establishing provisional eligibility criteria and a referral process for those children who may be awaiting a diagnosis of permanent hearing loss; this may help to ensure enrollment in EI by 6 months of age.

Other factors that contribute to a delayed EI enrollment include a refusal of EI service, delays due to denial of the hearing loss diagnosis, and lastly an infant's degree of hearing loss. Degree of hearing loss has become a frequent reason for families to either refuse or delay intervention services. For instance, in 2017, 15 of the 35 infants diagnosed with hearing loss, had a slight and/or unilateral hearing loss. Only 10 of these children were ever enrolled in EI, 4 of these within 6 months of age. Of these 10 children who were ever enrolled, 7 have already been discharged. The population of children who have slight and/or unilateral hearing loss are both difficult to engage and retain in EI services. The EHDI program will connect with other states to hear more about strategies that have helped with engagement and retention and will also research best practices.

RI-EHDI complies with federal privacy regulations (FERPA) by collecting parent consent to share information between RI-EHDI and EI through an EHDI authorization form. Currently, the RI-EHDI parent resource specialist (PRS) is responsible for obtaining the signed authorization form, however EHDI PRS face challenges when they are unable to schedule a home visit to obtain the authorization form signed. To address this issue, RI-EHDI will work with EI on how the service provider working with the family can collect the signed consent.

Part C represents not only an opportunity to link previously identified children with early intervention services, but also exists as a system that can actively help to identify additional children with late onset or progressive hearing loss or children who were lost to follow-up after

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newborn screening. The current eligibility criterion is to document the diagnosis that makes the child eligible for services, however in the event a child receives a diagnosis of late on-set, EI will document it as a second or third diagnosis. The RI-EHDI will partner with EI in streamlining the current referral process for children who are D/HH in order to capture information relevant to hearing loss in the EI-IS system whether it is a diagnosis related to eligibility, a secondary or tertiary diagnosis.

Currently the EHDI programs will make a referral to EI when a child is newly diagnosed with hearing loss. The EHDI PRS will contact the family and offer a referral to Early Intervention. Once family agrees and provides a verbal consent, the PRS faxes a referral to EI. In efforts to ensure timely referral the EHDI PRS struggles at times confirming receipt of referral from EI. In order to ensure timely enrollment into EI, the EHDI program relies on KIDSNET documentation of an Individualized Family Service Plan (IFSP) date. For those children with a documented hearing loss, RI EHDI in collaboration with EI will perform a CQI project that will examine the referral and enrollment process to identify potential breakdowns. For instance, the infrastructure may need to be strengthened to improve the process that occurs when audiologists refer to Early Intervention. This may entail strengthening both the ways that referrals are made, as well as communication to parents/family members about EI. Parents are delaying and declining to engage in EI. RI-EHDI and EI will review discharge documentation of all families who declined services to better understand and address barriers to enrollment in EI. Another initiative RI-EHDI will explore, alongside EI staff, is a trial of provisional enrollment for those children who may be awaiting a confirmed hearing loss diagnosis in order to achieve enrollment in EI by 6 months of age.

Lastly, in order to coordinate with Part C, RI-EHDI will regularly participate in the Interagency Coordinating Council (ICC) meetings. This council is composed of representatives from organizations that serve the Early Childhood population, including Early Intervention providers, pediatricians, and the RI Parent Information Network. In addition, the Council includes parents of children who are currently or formerly enrolled in Early Intervention, parents of children with developmental delays, members of the RI state legislature, and staff from the Rhode Island Executive Office of Health and Human Resources, the lead agency for EI and the state Medicaid agency, the Rhode Island Department of Education, Head Start, the Department of Children, Youth and Families, the Rhode Island Department of Health, the Department of Business Regulations, RI KIDS COUNT, and the RI Office of the Health Insurance Commissioner. This Council offers RI-EHDI the opportunity to educate and emphasize the importance of the EHDI's continuum of care; to all stakeholders participating in the ICC. Moving forward RI EHDI will continue to participate in the Interagency Coordinating Council (ICC) meetings to engage and collaborate with Part C EI service providers. Since the ICC also acts as a sounding board for families and providers to discuss challenges and successes in their Early Intervention experiences, RI-EHDI will incorporate the attendance of both RI-EHDI Parent Resource Specialists (PRS).

Objective 1.2 Develop a state plan to expand the infrastructure, including data collection and reporting, for hearing screening for children up to age 3.

The RI Department of Health will develop a comprehensive state plan for Early Hearing Detection and Intervention in RI. According to the CDC, in guidance provided to Oral Health programs, a state “plan is a roadmap for accomplishing the goals and objectives that have been developed in collaboration with partners and stakeholders.” The CDC advises that the state plan

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“should be used to direct skilled personnel and funding decision,” and so that states can prepare “to effectively compete for funding and take advantage of opportunities.” A state plan also “demonstrates that mechanisms are in place to utilize resources...and should include state-specific data and should meet certain minimal criteria.”^{ix}

As RI does not currently have a state plan for the EDHI Program, the state will reach out to other states to determine if there are existing plans that RI could use as a guide. In addition, the RIDOH’s Oral Health program developed a state plan recently, which can also be used as a template. According to the Oral Health Program Manager, the program began to develop their state plan through meetings with the Oral Health Commission. The Commission met as a group to determine which topic areas were most relevant. The Commission then split into subgroups to develop objectives, which they presented to the larger group. The Oral Health State plan includes 5 goals and within those goals, there are recommendations, objectives, and activities.^x The team used data to guide their plan.

The RI EHDI program is fortunate to have a robust Advisory Committee, which will be used to develop the RI EHDI state plan. Members of the Advisory Committee include representatives from EI, community health centers, managed care, birthing hospitals, Medicaid, the Office of Children with Special Health Care Needs, the Commission on the Deaf and Hard of Hearing, the RI School for the Deaf, and cochlear implant centers. In addition, the Committee also includes pediatricians, parents, educators, linguists, audiologists, speech language pathologists, community service providers, midwives, and state maternal and child health leadership. Along with developing the plan, these same stakeholders will be necessary to help implement the plan.

In developing this plan, the EHDI program will include how the state infrastructure will be expanded. In addition, it will include the resources, key stakeholders, partnerships, and services necessary to implement the plan. It will include how the program will link with other programs throughout the state including EI, Family Visiting, Early Head Start (EHS), and WIC. The EHDI program will help guide the process.

In addition, although the state has two robust data systems, RITRACK and KIDSNET, the plan will include how information on how these can be improved, if necessary, to enhance data collection and reporting. KIDSNET is organizationally located in the Center for Health Data and Analysis (CHDA) at RIDOH. CHDA has extensive capacity to support data collection. Data are collected and entered into KIDSNET through both data transfer files and by community partners who have been given access to KIDSNET through a web portal. RI is currently in the process of integrating the functionality of RITRACK into KIDSNET to improve efficiency and reduce errors and delays associated with data transfer. The Centers for Disease Control and Prevention funding for EHDI activities provide significant support for data support, infrastructure and linkages. As part of the plan to expand infrastructure for data collection and data reporting, the EHDI program is currently exploring electronic transfer of diagnostic data from large hospital-based audiology departments. This systems integration along with data extraction from EHS agencies, will enhance the plan to expand the infrastructure for data reporting therefore effectively tracking results for hearing screening up to the age of three.

Objective 1.3: Establish and maintain partnerships for referring, training and information sharing with community partners and stakeholders. By the end of year 1, and revised annually, recipients should complete an assessment of current partnerships and identify key partners who could help address gaps in the EHDI system.

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RI currently maintains strong partnerships with community partners and stakeholders that are used for referrals, training, and information sharing; this is possible through the well-established EHDI advisory committee. Having a diverse range of stakeholders in the advisory committee allows RI-EHDI to partner with key stakeholders and to establish mechanisms that facilitate timely referrals, training, and information sharing. Data provided regularly to the EHDI Advisory Committee allows stakeholders to identify gaps in the system that need to be addressed.

As previously mentioned, the EHDI team provides ongoing trainings, educational presentations, and materials to stakeholders who work directly with families. Trainings and information sharing occur with the following early childhood providers, WIC, Family Home Visiting, EHS, early care and education providers, pediatric audiologists, speech language pathologists, EI providers, and birthing facilities. The EHDI program has also presented to physicians and stakeholders who are part of the Patient Centered Medical Home-Kids (PCMH-Kids) and to professionals participating in the LEND program. The purpose of the trainings is to update and educate the audience on the goals of the EHDI program and to provide information on early hearing screening, diagnosis, and intervention system for infants. In addition, training also reinforces the importance of screening follow-up, audiological evaluation, and referrals. Educational opportunities increase the visibility of the EHDI program, create networking opportunities, strengthen collaborative relationships with stakeholders and raise awareness about the importance of newborn hearing screening and timely follow-up.

There are specific partnerships already established to assist with referrals and engagement. For instance, the EHDI program currently has a workgroup focused on children who have a confirmed hearing loss. This workgroup reviews HL cohort data to confirm enrollment of EI by six months of age. During this project period, the EHDI program will continue to partner with EI to analyze the timeliness of early intervention services.

WIC, EI, and Family Visiting program providers work with many of the same families who are in need for hearing follow-up. WIC and Family Home Visiting are currently housed in the same division at RIDOH, the Division of Community Health and Equity (DCHE). All three programs are located in the Perinatal and Early Childhood Health team (PECH). CHE has a comprehensive approach to health promotion and prevention, and this is evident in the way that staff from different programs collaborate. For example, the RI-EHDI program staff at RIDOH, in collaboration with Family Home Visiting program, train home visitors on the 1:3:6 timeline recommendations and the risk factors for later onset hearing loss. In addition, the EHDI program works collaboratively with WIC and Family Home Visiting to locate families that may be LTF for hearing screening, diagnosis, or EI enrollment.

It is essential to continue to support this kind of collaborative work to ensure programs coordinate and policies and resources are aligned. Integration of RI-EHDI and Title V programs is also important to provide families with clear and consistent messages and information about the importance of follow-up screening, care coordination, and enrollment in EI services, as well as information about programs for children with special health care needs. Although the RI-EHDI program currently has a good number of partnerships with community partners and stakeholders, there is room for improvement. By the end of the 1st year of the grant, RI will complete an assessment of current partnerships and will identify key partners who could help address gaps in the EHDI system.

Objective 1.4: Convene the RI EHDI Advisory Committee quarterly to advise on programs,

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objectives, and strategies

Since RI passed universal newborn hearing screening legislation in the early 1990s, RI has conducted and maintained an EHDI Advisory Committee. The Rhode Island Newborn Hearing Screening statute requires the Committee to meet at least four (4) times per year. As mentioned in Objective 1.3, Rhode Island's diverse Advisory Committee membership includes representatives from numerous key stakeholder groups. The EHDI program ensures that there are interpreters and other accommodations available for the Committee meetings. Close to 30% of the advisory committee is comprised of parents of D/HH children or D/HH adult members. In accordance with public body state law, the Committee posts meeting notices and records and post minutes within 14 days on the Secretary of State's Open Meetings website.

In 2018, the EHDI Advisory Committee created sub-committees/work groups focused on matters related to the medical-home, parent engagement, and diagnostics and the EHDI system. The subcommittees' goals are to strategize and ensure the development of an increased knowledge and engagement within the EHDI system by ensuring parent involvement at all levels of the EHDI system. This coordination will support and promote statewide EHDI goals within the context of specific community needs.

Members of the Committee will be influential during this project in expanding the current infrastructure, by providing the necessary guidance on topics related to family engagement, leadership, family support and most importantly gaps in EHDI systems and other emerging issues. In addition, the Committee will be an integral part of developing the state plan. The EHDI program and Committee members will identify and invite any key partners who are not currently part of the Committee and will continue to ensure that at least 25% of the members are parents of children who are D/HH and adults who are D/HH.

Objective 1.5: By the end of year 2, develop a plan to address diversity and inclusion in the EHDI system to ensure that the state or territory's EHDI system activities are inclusive of and address the needs of the populations it serves including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.

The RIDOH intends to develop a comprehensive plan that addresses diversity and inclusion for RI-EHDI that involves a wide range of stakeholders including families. The plan will identify the role of RI's EHDI program in maintaining a coordinated system of services and delineate the roles of other stakeholders. The plan will highlight the role of family support organizations such as the RI Parent Information Network (RIPIN), RI Hands and Voices (RI H&V) and the partnership with the Family Leadership in Language and Learning (FL3 Center). In developing the plan, the program will utilize EHDI data to identify subpopulations vulnerable to disparities and to determine what sort of continuous quality improvement work needs to be done in order to decrease the differences in access to, use, and outcomes of service activities.^{xi}

Although RIDOH and the EHDI program are committed to eliminating health disparities and promoting health equity and have taken some strides towards doing this through current work, the EHDI system does not have a specific plan to address diversity and inclusion in the EHDI system to ensure that the state's activities are inclusive of and address the needs of the population it serves. The program will collaborate with other systems that currently have a plan, will seek technical assistance, and will conduct research to, by the end of year 2, develop a plan to address diversity and inclusion.

In addition, the DCHE's commitment to eliminate health disparities and promote health equity ensures that all Maternal and Child Health and early childhood programs operate in an environment that has organizational behaviors, practices, attitudes, and policies that respect and respond to the cultural diversity of communities and families served by them. RIDOH is

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committed to ensuring access to quality services, information, and materials that are delivered in a manner that considers the language needs, cultural richness, and diversity of populations served. Health equity is a priority for the RIDOH and as such in 2016, the RIDOH Health Equity Institute, was established. The Health Equity Institute seeks to foster innovation and community engagement across RIDOH towards a vision of a truly healthier Rhode Island. As part of the commitment towards inclusion and addressing the needs of the populations they serve, agencies implementing RIDOH programs or services adhere to the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care. According to the US Department of Health and Human Services, Office of Minority Health, CLAS standards “aim to improve healthcare quality and advance health equity by establishing a framework for organizations to serve the nation's increasingly diverse communities.”^{xii} RIDOH staff monitors agency compliance with CLAS. Training on health equity and cultural competency is also required for agencies that receive RIDOH funding and other community partners.

Access to quality, comprehensive, coordinated community-based systems of services that are family-centered, community-based, and culturally competent is essential. It is clear based on the needs assessment that RI-EHDI does need to focus on ensuring that all families, particularly those who face disparities, have equal access to all services. By developing a plan to address diversity and inclusion, RI-EHDI should better be able to meet all families’ needs.

Objective 1.6 Develop and implement a strategy to monitor and assess program performance in meeting the stated program purpose and objectives that would contribute toward continuous quality improvement (QI) throughout the period of performance. Identify existing gaps and challenges in the state’s EHDI program and use a QI approach to address unique needs of the state’s system of care.

The RI EHDI program has developed a Quality Improvement (QI) Team which meets monthly to review EHDI data and monitor program activities. Data will be collected in the EHDI-IS system and quarterly data, as well as Quality Improvement data/trends, will be reviewed by the team regularly and presented to the Advisory Committee. Data evaluation will determine if activities implemented through this grant were successful in engaging providers to support a comprehensive system of care, reducing the lost to follow-up rate, getting infants into services at the earliest possible opportunity and meeting the needs of infants and families. The EHDI QI team will meet frequently to plan and assess progress in meeting the program purpose and, as needed, will plan CQI activities to try to improve processes in order to meet the program goals. In addition to the EHDI QI team, the EHDI Advisory Committee meets quarterly and EHDI evaluation is included on the agenda. All stakeholders will be key in developing strategies to monitor and assess program performance.

Fortunately, the RIDOH Newborn Screening Program works within a state context where there is robust support for CQI activities. There is a goal at the state level that all state agencies and programs utilize continuous quality improvement strategies. In order to ensure process improvement and delivery of high-quality services for Rhode Island residents, Gina Raimondo, the Governor of RI, and Dr. Nicole Alexander-Scott, the Director of the RIDOH, have both identified CQI as a state priority. In 2015, Governor Gina M. Raimondo issued the “Lean Government Initiative” Executive Order 15-09 for all executive branch departments and agencies in the Governor’s Cabinet. Executive Order 15-09 aims for Rhode Island government to adopt a culture of continuous improvement to provide effective and efficient services for the State of Rhode Island. The Order states that all levels of employment within state agencies should be active in continuous quality improvement activities to improve business processes, implement

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process improvement reviews to be responsible for RI customers for optimal service outcomes, review existing processes with Lean methodology, partner with local business leaders for process improvement, and engage in cross-system collaboration with all executive level departments and agencies for process improvement.

Continuous quality improvement (CQI) is a systematic approach to improve program services and increase positive outcomes for children and families. The EHDI program will develop a CQI plan, which outlines not only what data/benchmarks the program should regularly collect, but how often to review it. If data are regularly reviewed, this will allow the team to begin a CQI project as soon as a need is identified. Within the past few years, the EHDI program has conducted multiple successful CQI projects. For instance, a CQI initiative was recently implemented at the largest birthing hospital to focus on improving the diagnostic refer rate in the well-baby population. As a result of the CQI project, the hospital changed the method of outpatient screening done at the hospital. In addition, in 2018, the EHDI program, through a CQI project, collaborated with the EI program to improve the consent process.

During the next 4 years, RI will focus on the following areas for improvement: 1) Improving the process by which infants who failed the NBHS are diagnosed in order to decrease the number of infants who are LTF/LTD; 2) Improving the diagnostic documentation process to decrease the number of children who are LTD; 3) Improving the EI referral process to increase the number of infants diagnosed with hearing loss who are receiving services by 6 months of age.

In 2017, there were 151 children who did not receive a confirmed diagnosis; 15 of these children never received a diagnostic evaluation appointment. Data show that children are more likely to receive a diagnostic evaluation if an appointment is made prior to hospital discharge. In 2017, there were infants who did not receive a confirmed audiological diagnosis but left diagnostic centers prior to receiving a follow-up appointment. The EHDI program will participate in a CQI project, in which the team will examine the entire process of scheduling evaluations at diagnostic centers. In addition, the team will review the process for rescheduling appointments for those families that miss their diagnostic appointments. Appointments for which the family is a "no show" are often associated with children who in the end are LTF.

Along with focusing on the scheduling process, RI will work on improving the diagnostic documentation process to decrease the number of children who are LTD. Currently, RI-EHDI is working with the 2 main diagnostic centers regarding data extraction of hearing assessment evaluations in their electronic medical record. The purpose of this project is to facilitate direct data extraction from the diagnostic center's electronic medical record (EMR) into the EHDI-IS (KIDSNET) system thus eliminating the need for data duplication. In addition, the goal is to improve the timeliness of reporting. However, the RI-EHDI program may need to conduct a CQI project on the reporting process to further decrease the average number of days between final hearing screening date and first diagnosis.

RI-EHDI will, with EI staff, conduct a CQI project to improve the EI enrollment process for those children who have been diagnosed as being D/HH. The team will focus on improving the referral process; in addition, the team will test whether provisionally enrolling children who are waiting for a confirmed hearing loss diagnosis improve the rate of EI enrollment by 6 months of age. The RI team will report annually to HRSA on progress towards addressing these issues using a QI approach and will include goals, methods, timelines for improvement, and stakeholders involved.

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Objective 1.7 Develop, maintain, and promote a RI-EHDI website that is user friendly with accessible and culturally appropriate and offer accurate, comprehensive, and evidence-based information for families.

During this project period, RI-EHDI will establish a digital presence for the program. A website developer from RIPIN will develop the website using the EHDI Website Resource Guide and will include the critical components as identified by the guide. These include: 1) an overview of RI's EHDI program; 2) information for various stakeholders including families, health care providers, and EI providers; and 3) information about the EHDI process. In developing this website, the RI-EHDI program will focus on the design, layout, and accessibility of the website. Along with using the guide, the EHDI program will use the quality state EHDI websites, as designated by the National Center for Hearing Assessment and Management at Utah State University, as a guide in designing its own. The EHDI program will ensure that the website is user-friendly, culturally appropriate, accurate, comprehensive, and provides evidence-based information for families. Once the website is developed, as the guide suggests, the program will continue to monitor it to ensure that it is meeting the intended goals, and if not, the team will conduct a CQI project to test and make changes. The Parent Resource Specialists, as mothers of D/HH children, will assist in providing caregiver perspectives about the website.

Specifically, the website will include a calendar of events, which will note dates of important events related to EHDI. It will include a contact page, which will allow parents and providers to get in touch with the RI-EHDI program, local parent support organizations, and specialized programs. Once developed and tested, the website will be promoted using print materials, social networking sites, and electronic media. The EHDI program will ensure that the website is easily found in an electronic search. The RI-EHDI website will be maintained by EHDI staff, including the PRS, who will be able to post, create new pages, add new resources to the knowledge base, and add events to the calendar. Since EHDI programs receive federal funding, all EHDI websites must comply with Section 508 of the U.S. Rehabilitation Act Standards.^{xiii} To comply, RI-EHDI will incorporate the add-on User Way Website Accessibility Widget, which enhances the accessibility of the site for people with disabilities. The software allows RI-EHDI to improve its compliance with the Web Content Accessibility Guidelines. The RIPIN website developer will make any change in design and/or layout.

Objective 1.8 Plan for project sustainability after the period of federal funding ends.

Rhode Island continues to explore opportunities to secure and sustain funding for key activities within the RI-EHDI system. As suggested in the NCHAM *Resource Guide for Early Hearing and Detection*, "Financing and Sustainability" chapter, the RI-EHDI program will develop a sustainability toolkit, which "is a complete plan that addresses a host of EHDI program issues, including financing and sustainability." As suggested the toolkit will include "summary reports of key program indicators and success" and "a specific plan that addresses funding and fundraising opportunities."^{xiv} In addition, the plan will include key components of the project that demonstrate improvements for D/HH children. The plan will also include a focus on sustainability for the website.

RI will continue to work with state agencies and public and private partners to evaluate the impact of RI-EHDI system strategies, services and interventions that have led to improved outcomes for deaf or hard of hearing children and their families in order to create a compelling argument for sustaining the RI-EHDI system enhancements. Chapter 35 of *A Resource Guide for Early Hearing and Detection*, "Financing and Sustainability," emphasizes the importance of

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maintaining stakeholder support. The guidance indicates that “screening programs should have relevant statistics available for use in education of administrators and providers. Positive identification of hearing loss and the associated human impact stories need to be presented, making the impact of the screening program real for all stakeholders.” In addition, the NCHAM provides additional financial sustainability suggestions including determining if there are other sources of funds for items such as equipment. Suggestions, which the RI EHDI program will explore, include looking for service clubs and/or hospital foundations, auxiliary, or other volunteer groups that could raise funds for equipment needs. ^{xv}

The EHDI program’s sustainability plan will include maintaining capacity to provide family support and engage adults and families with children who are D/HH. The RI H&V Chapter has been recently established and authorized by national Hands & Voices (H&V). The sustainability plan will also focus on ensuring ongoing partnerships with other family-based organizations including RIPIN and the FL3 Center.

Goal 2: Engage, educate, and train health professionals and service providers in the EHDI system.

Objective 2.1 and 2.2 Conduct outreach and education to health professionals and service providers in the EHDI system.

During this grant period, RI-EHDI will continue the outreach, education, and training that is currently taking place. The RI-EHDI team provides ongoing training to primary care providers on the KIDSNET Follow-up Report, which allows pediatricians to access a practice-specific report to assist with engaging families on follow-up. In addition, it serves as a reminder to medical providers on the importance of timely screening, diagnosis, referral, and enrollment into EI services.

In RI, as of April 2019, there were 37 practices participating in the state’s PCMH-Kids Initiative. Within these 37 practices, there are over 260 pediatricians and trainees who care for over 110,000 children, representing more than 80% of the state’s Medicaid population.^{xvi} The EHDI program has presented to the PCMH-Kids Stakeholder Committee and will continue to use this engaged group of pediatric health care providers to better understand where there are gaps in provider understanding related to newborn hearing screening and follow-up. The RI-EHDI program will collaborate with the PCMH-Kids group to work with those practices who have the largest lost to follow-up population and to remind them of the importance of timely screening, diagnosis, referral, and enrollment into EI services as well as the need for hearing screening up to age 3. Finally, the EHDI team will emphasize the benefits of a patient/family-centered medical home and family engagement in the care of a D/HH child.

Since 2016, HRSA has funded the LEND program in Rhode Island. For the past 3 years, the RI-EHDI program has provided in-person workshops to the LEND program. The EHDI team, which is composed of medical providers, parents, and community partners, has, and will continue to, participate, on an annual basis, in a two-day series presentation for LEND fellows. The LEND presentations allow the EHDI team to inform a multi-disciplinary audience about EHDI program goals and objectives and processes.

In RI, KIDSNET aggregates data about children’s health and development to improve coordination of care and access to services. The KIDSNET Provider Relations team trains health professionals and service providers and promotes the use of KIDSNET to identify children in need of preventive health care and associated follow-up. This includes newborn hearing

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screening follow-up. KIDSNET users can look at individual patients and run practice/agency level reports to identify children in need of screening or diagnostic audiology. Also available through KIDSNET is an on-line training module for audiologists on how to access screening results and enter diagnostic information.

The EHDI program has also provided training to the Department of Children, Youth & Families (DCYF), through a web-based training module. DCYF is the state child welfare, children's mental health and juvenile corrections services agency; by providing this training, EHDI ensures that more children involved with the agency receive the necessary follow-up. During this grant period, the RI-EHDI program plans to provide additional web-based training modules to more user groups such as primary care providers and EI.

The EHDI program will continue to actively participate in the EI Community of Practice (CoP) group in order to educate, train, and provide resources to those working with D/HH children between the ages of birth to three. In addition, the RI-EHDI team will provide training to all new EI employees regarding the 1-3-6 guidelines and available resources.

RI routinely provides, and will continue to provide, educational presentations and materials to WIC, home visiting programs, EHS, Child Care, pediatric audiology providers, speech language pathologists, and other relevant programs. During the next 4 years the RI-EHDI program will focus on increasing the number of health professionals and service providers trained. The EHDI program will continue to use, and will modify as needed, the already developed comprehensive PowerPoint presentation. The presentation, which is provided by the EHDI team, is organized around seven topics, including: 1) newborn hearing screening; 2) the importance of early identification of hearing loss; 3) timely early intervention treatment and services; 4) tracking and surveillance; 5) early exposure of language for speech/language development, 6) importance of parent engagement; 7) and communication opportunities available to families. The RI-EHDI will also identify a D/HH adult who could be part of the presentation with the goal of incorporating the perspective of a deaf adult.

The RI-EHDI program also distributes, to stakeholders, an electronic newsletter, which includes information relevant to the 1-3-6 guidelines as well as upcoming events. The program will continue to distribute the newsletter and plans to cover other relevant topics. In addition, the team plans to post the newsletter on the RI-EHDI website, once it is developed. The EHDI team currently posts, and will continue to do so, on the RI-EHDI Facebook page.

Goal 3: Strengthen capacity to provide family support and engage families with children who are D/HH as well as adults who are D/HH throughout the EHDI system.

Objective 3.1 Engage families throughout all aspects of the project, involving family partners in the development, implementation, and evaluation of the EHDI Program.

RIDOH has a strong commitment to ensuring that there is family engagement throughout the development, planning, implementation, and evaluation of the EHDI program. Frequently, programs and services are developed without family input and adequate consideration for family needs. This can result in programs that do not fully or effectively meet the needs of children and their families, including newborns/infants who are D/HH. Hearing screening, evaluation, diagnosis, early intervention, and specialized support programs must be reflective and incorporate the needs of families with children who are D/HH.

The RI-EHDI program will continue to support family engagement and family partnerships at the national, state, and local level. As of 2018, Rhode Island has supported parents to attend the EHDI Annual Meeting and the H&V Family leadership Conference. In

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addition, funds have been allocated for parents to attend the upcoming Family Leadership Conference. In addition, prior to scheduling any event or meeting, RI-EHDI make appropriate arrangements for necessary interpreters including Spanish and American Sign Language.

In 2018, the RI-EHDI advisory committee implemented a sub-committee/work group focused on parent engagement activities. Through the sub-committee, parents provided input on the development of a shared plan of care (SPoC), which outlines the actions, needs, and goals, along with the steps to meet them. Prior to drafting the SPOC template, the EHDI PRS and parents from the subcommittee helped to develop and distribute a survey that was used to assess parents' perspectives and gather their personal experiences through the EHDI system. Currently the SPoC tool is being tested with 3 families who have children diagnosed with hearing loss. The experiences of the families who have used the SPoCs will be used to develop the final document.

Parents were also offered the opportunity to review the CDC's EHDI-PALS (Pediatric Audiology Links to Services) mobile application, which is used to link caregivers to information, resources, and services for children with hearing loss. The parents' perspectives allowed RI-EHDI to determine whether to pilot the application for follow-up purposes. RI-EHDI will continue its current practice of including parents in making any policy, material, or systems change.

Objective 3.2 Conduct outreach and education to inform families about opportunities to be involved in different roles within the state EHDI system and collaborate with various leaders and policy makers in addressing the challenges to and providing solutions for the EHDI system.

The RI-EHDI program will continue to conduct outreach and education to inform families about opportunities to be involved in different roles within the state EHDI system. Over the last several years, the team successfully recruited families of children who are D/HH to engage in the RI-EHDI Advisory Committee. The EHDI team offered interpreting services, a stipend and childcare services to those caregivers who participated. The team developed a parent flyer to recruit new members, which was emailed to stakeholders and posted on RIPIN's and EI's Facebook pages. The recruitment approach was initially effective at increasing the number of parents. Prior to the recruitment effort, there was only 1 parent on the Advisory Committee. This number increased, so that there has been a total of 17 different parents who have attended, however, there are only several that come regularly. Some parents initially came and haven't returned. The RI-EHDI program will focus both on increasing the number of parents that attend as well as ensuring that they stay engaged.

The RI-EHDI program maintains a partnership with FL3 Center. In 2017, FL3 conducted a needs assessment with the goal of looking more closely at the needs of families, family-based support organizations, and EHDI programs. Many parents indicated that there was not enough communication about opportunities to participate. Other factors included lack of time and/or training, the confidence and/or skills to participate, and/or lack of clarity on their role. RI will review the suggestions noted in the needs assessment and develop a plan about how the EHDI program can better outreach to families.^{xvii}

The EHDI program will continue to make positive changes in communication methods with families. Since 2016, the EHDI PRS have collected email addresses from willing families. Through email, families are informed about events, meetings, trainings, workshops, and resources. In addition, this has allowed the EHDI team to use Eventbrite, an event management and ticketing website, to survey attendees and provide mass email invitations. In 2018, the RI-EHDI program purchased ZOOM, a secure video-conference service, which the team will

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continue to use. This platform allows families to participate virtually when they are unable to attend a meeting in-person.

Social media is important in engaging families. The PRS posts up-to-date local and national information, promotes events, adds new resources, and invites families to educational workshops, trainings, and social events on the RI-EHDI Facebook page, which went live in 2015.

Objective 3.3 Facilitate partnerships among families, health care professionals, and service providers to ensure that providers understand the best strategies to engage families.

The RI team will facilitate partnerships among families, health care professionals, and service providers to ensure that providers understand the best strategies to engage families. The needs assessment conducted by FL3 showed that, in order to engage families in services, they need to be offered comprehensive information about the services and support at different points in their child's life. The information needs to be clear so that families understand the system. In addition, families must also receive contact and support from other parents who share their lived experience.^{xviii}

To address this, as mentioned previously, in 2018, the parent engagement subcommittee asked parents to provide input on the development of a shared plan of care (SPoC). Research has shown that a SPoC improves family-clinician relationships, supports family-centered care, and provides information that enhances the planning and delivery of health care services that meet the medical and social needs of children, youth, and their families. A SPoC is a living document that can change as the child moves through the system. Families, health care professionals, and service providers work together to develop the SPoC, which is used to ensure that the services provided to the family are comprehensive and coordinated. It includes specific information about the child's health and development. It can be updated and redesigned according to the child's developmental trajectory and each transition. The SPoC results from a family-centered, team-based process, involving families, clinicians, and coordinators.^{xix}

The RI-EHDI program is currently piloting the use of the SPoC with 3 parents. The EHDI program is collecting information about the families' experience with the SPoC and will use that to modify the plan, as needed. Once the pilot has been completed, the EHDI program will use the SPoC with all families who have a child identified with hearing loss, with the end goal of improving the care coordination process for families. The EHDI Parent Resource Specialists will be influential in the implementation of the SPoCs by providing appropriate support on the tool's benefits as well as how to use the tool to guide decisions. For example, EHDI PRS will be present when EI service providers are trained on the use of the SPOC. Having the PRS present during the trainings will allow for them to share their personal perspectives on the benefits of the use of the SPOC.

Along with the SPoC, the RI EHDI program will consult with parents on the development of a roadmap for families, which is a single document that visually provides information on the pathway that children with hearing loss typically take through screening, diagnosis, and intervention. In a project that the National Initiative for Children's Healthcare Quality (NICHQ) designed to test strategies to reduce loss to follow-up after newborn hearing screening, through various Plan-Do-Study-Act Cycles, parents provided feedback on their experience with the roadmap. The roadmap was initially designed to be used for parents, but when tested as a shared tool for both parents and professionals, it was found to be extremely useful. In the test, it became clear that some of the parents did not understand the difference between the various professionals

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who work in the EHDI system and the need for different providers to be engaged in the assessment process. ^{xx}

Objective 3.4 Use 25% of grant funds for family engagement and family support activities

The RI EHDI program has made it a priority to strengthen parent support for families of newly identified children. RI currently dedicates 25% for family engagement and family support activities and will continue to do so. For the past decade, in partnership with RIPIN, RIDOH has prioritized supporting family engagement and parent leadership at both the state level and in communities. RIPIN is a large, well-established parent support organization that has statewide-reach to support parents with special health care needs as they navigate the system of services and access services for their children. RIDOH provides funding to RIPIN to manage the RI chapter of Family Voices (FV), which supports family-centered care for all children and youth with special health care needs and/or disabilities. RIDOH also provides funding to RIPIN to support Family/Peer Resource Specialists, a network of parents who can provide information and informal support to families of children with special health care needs.

Since 2007, the RI-EHDI program has used funding from HRSA to support PRS (parents of children with hearing loss). The PRS are employed by RIPIN, to work in the state's EHDI program. The PRS have supported parents of children who fail a newborn hearing screen to access diagnostic services as well as supported families of children who are D/HH to access services. The role of the Specialists is to provide peer-to-peer support to families of children who experience hearing loss and to facilitate peer-to-peer support with other families. Currently, the positions are filled by two mothers who have children who are D/HH: 1) Marzena Piorkowski (See Attachment 3) is the mother of three children, two of whom have special needs, including hearing loss. She speaks English and Polish. She has six years of experience with EI as well as 15 years of experience with Individualized Education Plans (IEPs) and general education (504s) accommodation plans. 2) Gladys Medina is the mother of two daughters and a son who is deaf, bilaterally implanted and signs as his mode of communication. Gladys is Hispanic, and she speaks, reads and writes in both English and Spanish. In addition, she signs using American Sign Language (ASL). (See Attachment 3).

The Rhode Island EHDI program will continue to use the PRS as partners in engaging families; this work has been shown to reduce the state's loss to follow-up rate. In addition, to the work described previously, the Specialists are responsible for providing resource information to families of newly identified children who are D/HH as well as those D/HH children who are approaching their 3rd birthday as they transition from Part C to Part B services. The packets include information about services available through EI, including RI Family Sign, Auditory/Oral services, Perspectives, and the Parent-Infant Program (PIP), as well as how IFSPs are developed. The PRS also provide information regarding virtual learning sign language classes (Sign It), auditory oral classes (Hear to Learn), community resources, and the peer-to-peer support offered through H&V.

The RI-EHDI program encourages and supports parent leadership development. EHDI Parent Resource Specialists have participated, and will continue to participate in, the Annual EHDI meeting. Dedicated funds will be allocated to ensure, at a minimum, 1 family leader attends the annual meetings. Additional funds will support leadership training, stipends for parents to participate in advisory committee meetings, access accommodations, translations, family social and educational events, family support and development of materials that are family-friendly and inclusive of family needs. The RI-EHDI program also hosts peer support

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groups which offer families an easy way to connect with others that have similar experiences. RI-EHDI parent facilitators use their experiences to guide families towards appropriate resources and to build self-advocacy skills through peer to peer support.

In August of 2019, RI became an official Hands & Voices (H&V) Chapter and received authorization to use the name Rhode Island Hands & Voices; an agreement between H&V, Inc. and RI H&V is currently in place. RIDOH will partner with RIPIN to support the development of the RI H&V Chapter. H&V is a parent-driven organization that provides families with a safe place to explore options, get emotional support, and learn from one another. The RI H&V board includes parents, professionals, and adults who are deaf or hard of hearing, which aligns with the H&V value and policy of D/HH infusion. Through this funding opportunity, RI will be able to dedicate funds to train board members in leadership skills, to develop communication outreach materials, to organize social events, and to provide support groups for families.

Families with children who are D/HH also benefit from access to support, mentorship, and guidance from adults who are D/HH.^{xxi} A 2018 needs assessment, completed by the Family Leadership in Language and Learning (FL3) Center, revealed that “of families surveyed with children who are D/HH under the age of 6, only 28% of the families were offered formal parent-to-parent support program services, and only 27% of the families were offered access to an adult who is D/HH as a mentor, role model, or guide.”^{xxii} Therefore, RI is currently in the early stages of exploring and developing a plan with the Gallaudet University RI Family Sign Language Program (RIFSLP) to expand the curriculum of its formalized trained deaf mentorship program. A deaf mentor “provides family-centered, home-based, and curriculum-led early education in the home, focusing on visual communication, American Sign Language, and bridging and navigating deaf and hearing experiences with the families with deaf children.”^{xxiii}

Objective 3.5 Consult with the HRSA-20-051 recipient (the Family Leadership in Language and Learning (FL3 Center)) for resources, technical assistance, training, education, QI and evaluation to strengthen the infrastructure and capacity for family engagement and family support in the state.

The purpose of the FL3 Center is to provide technical support to national, state, territory, and local EHDI systems of care in order to increase family engagement and leadership, and to strengthen family support within EHDI programs. RI will partner with the FL3 Center for ongoing leadership training and evidence-based and informed practices, policies, tools, and resources. This partnership will help RI-EHDI address program objectives and strengthen the capacity to both provide family support and engage D/HH adults and families with children who are D/HH throughout the EHDI system. The EHDI program will collaborate with the FL3 Center to arrange educational and leadership trainings and webinars. RI-EHDI will dedicate funds for the FL3 Center to train RI parent leaders on leadership and other important skills.

Goal 4: Facilitate improved coordination of care and services for families and children who are D/HH

Objective 4.1 Assess the status of coordination across early childhood programs and develop a plan to improve coordination and care services through a variety of mechanisms based on the current level of integration across programs

The RI EHDI program currently provides training and shares information and data with early childhood programs and providers including EHS, EI, WIC, the Family Home Visiting

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program, and pediatric primary care providers. The EHDI program maintains data sharing agreements with all EHS programs and actively collaborates with the program. All EHS agencies have on-line access to KIDSNET, which contains information about the newborn hearing screen and some information about follow-up services. Along with EHS, RI-EHDI collaborates extensively with Early Intervention through active participation in the Community of Practice (CoP) group within EI; the CoP group works to educate, train, and provide resources to those working with D/HH children aged birth to three. In addition, the RI-EHDI program staff at RIDOH, in collaboration with Family Home Visiting program, train home visitors on the 1:3:6 timeline recommendations and the risk factors for later onset hearing loss.

In addition, RI plans to partner with the Early Childhood Hearing Outreach (ECHO) Initiative, which focuses on ensuring that early childhood providers understand the benefits of periodic hearing screening in a variety of health and education settings. The ECHO Initiative trains early childhood providers on how to implement OAE hearing screenings for children who are between 0 and 3 years of age. ECHO has already offered web classes and self-guided instruction to professionals in RI who are interested in developing their competence in conducting OAE hearing screening for children birth to three years of age.

RI continues to support the implementation of health information technology within the EHDI program to improve access to services and information sharing. KIDSNET contains information on children's preventive health services for all RI children born on or after January 1, 1997. Currently it links data from thirteen different programs (newborn bloodspot, hearing and developmental screening, vital records, home visiting, Head Start, Cedar, immunization, lead screening, WIC, Asthma, Child Outreach, and Early Intervention) as well as having indirect connections with birth defects and foster care data. Because of the integrated nature of KIDSNET and easy on-line access, medical homes, child health programs, EI, 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 who are missing or need follow-up. Data entry capacity for audiology reporting and a variety of automated import and other batch processes exist on the server, including processes to import vital records, birth and Early Intervention data, as well as to exchange data with RITRACK.

During the grant period, the RI-EHDI program will, along with stakeholders, assess the status of coordination across early childhood programs and develop a written plan to improve coordination and care services through a variety of mechanisms. The program has already planned to improve data coordination with EHS. To ensure that information flows in both directions, the KIDSNET team will work with the EHS agencies to electronically send EHS enrollment data to KIDSNET. Once electronic submission is accomplished, this will enable the EHS programs to run the EHDI follow-up report on their enrolled children. In addition, to developing a plan to improve coordination and care services, by the end of year 3, the RI-EHDI team will demonstrate evidence of implementing the plan through documentation of formal communication, training, referrals, and/or data sharing.

In addition, RI plans to partner with the Early Childhood Hearing Outreach (ECHO) Initiative, which focuses on ensuring that early childhood providers understand the benefits of periodic hearing screening in a variety of health and education settings. The ECHO Initiative trains early childhood providers on how to implement OAE hearing screenings for children who are between 0 and 3 years of age. ECHO has already offered web classes and self-guided instruction to professionals in RI who are interested in developing their competence in conducting OAE hearing screening for children birth to three years of age.

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Goal 5: Participate in Annual EHDI meeting and work with the National Technical Resource Center

Objective 5.1 Participate in the Annual Early Hearing Detection and Intervention (EHDI) Meeting.

The EHDI team has allocated funds for 1 to 2 staff members and 2 parent leaders to attend the annual EHDI meeting, which the team regularly attends. This event provides an opportunity to learn from the formal presentations as well as from other teams that attend.

Objective 5.2 Work with the HRSA-20-048 program recipient (the EHDI National Technical Resource Center (NTRC)) to implement the various initiatives.

The RI EHDI Program has collaborated extensively, and will continue to work, with the National Technical Resource Center (NTRC) for technical assistance on implementing the described initiatives. NTRC resources have been invaluable for planning and policy development, implementing new strategies, and quality improvement.

WORK PLAN

Newborns and infants in RI who are identified as deaf or hard of hearing receive services from many professionals including Early Intervention providers, audiologists, and specialty providers related to their hearing needs. They may also receive other early childhood services such as Family Home Visiting and/or WIC or be in early care and education. Therefore, continued development of an integrated mechanism for sharing health and other relevant information, such as KIDSNET, and implementation of evidence informed strategies for information sharing and linkage will allow a greater number of professionals to access information about children and families to better ensure that they receive coordinated care within a comprehensive system. The activities within the work plan will be implemented in order to achieve the program goals and objectives listed below.

The goal of the program is to support the development of statewide programs and systems of care to ensure that children who are D/HH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social and emotional development.

RI's specific targets that will be achieved through the methods proposed below are:

- By March 31, 2021, to complete a newborn hearing screen on 95% of the infants by 1 month of age. Between March 31, 2021 and March 31, 2024 to increase this rate by 1% each year.
- By March 31, 2024
 - To achieve a minimum rate of 85%, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.
 - To achieve a minimum rate of 80%, the number of infants identified to be D/HH that are enrolled in Early Intervention services no later than 6 months of age.
 - To increase by 20% from baseline, using data collected from year 1 as baseline data, the number of families enrolled in family-to-family support services by no later than 6 months of age.

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- To increase by 10% from baseline, using data collected from year 1 as baseline data, the number of families enrolled in D/HH adult-to-family support services by no later than 9 months of age.
- To increase by 10% from baseline, using data collected from year 1 as baseline data, the number of health professionals and service providers trained on key aspects of the EHDI program.

The activities within the work plan will be implemented in order to achieve the program goals and objectives listed in the work plans. The means of measurement of success for the quality improvement strategies and anticipated spread of successful strategies will be provided. (See Attachment 1) for the timeline for each of the project goals and objectives.

RESOLUTION OF CHALLENGES

Discuss challenges that you are likely to encounter in designing and implementing the activities describe in the workplan, and approaches that you will use to resolve such challenges.

Over the years RIDOH has worked to develop and implement a system for screening, referral and follow up for infants born in RI. Challenges are inherent when working with multiple partners across multiple systems, agencies, communities and disciplines.

1-3-6 system

As part of this workplan, the RI-EHDI program will work with the birthing hospitals, the NICU, in particular, audiologists, and EI to improve certain processes in order to improve that children are screened, diagnosed, and enrolled in early intervention services as early as possible. As part of this, the RI-EHDI program plans to collaborate with EI to explore the possibility of changing the referral process and parent consent for release of information as well as establishing provisional eligibility criteria while children are waiting a confirmed diagnosis. Changing systems, including policies and programs of large programs and agencies, can be challenging. Agencies have developed policies and systems that respond to both federal mandates and state mandates, therefore it can be difficult to easily make a change. The team will work to maintain ongoing relationships, such as through participation in the EI CoP and the ICC, in attempting to make these changes.

Engaging Stakeholders

Documenting results of screening, rescreening, audiologic evaluations, amplification fitting and early intervention in the state data tracking and surveillance system is critical for reducing loss to follow-up in the EHDI process. State legislation in Rhode Island mandates newborn hearing screening. Reporting of birth defect (hearing loss) is also required. However, there are no fiscal or other consequences for institutions and individuals who do not report screening or birth defect results. To address this challenge, the EHDI program will continue to provide training on the use of KIDSNET to primary care provider staff and audiologists. Training will emphasize the importance of prompt entry of information for all children regardless of age, the need for detailed documentation and the valuable role of staff in reducing lost to follow-up.

Development of EHDI program website

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The visibility of the state's EHDI program will be enhanced by an EHDI website. During the first year the EHDI program will work with key stakeholder representatives who are willing to participate in the development of the website. A website is a dynamic tool used to provide information and resources, because of this, it can be challenging to maintain the website. The Parent Resource Specialists will be charged with updating the website on a regular basis. In addition, the EHDI team will develop a sustainability plan for the website.

Expanding screening up to age 3

Newborn Hearing Screening can only identify about half of congenital hearing loss, leaving the remainder to fall under the late onset or progressive hearing loss. Since 1992, RI has provided Universal Newborn Hearing Screening for all infants at time of birth. However, in 2017, the Reauthorization of the EHDI Act expanded the target population for hearing screening beyond newborns to include young children up to the age of 3.^{xxiv} Rhode Island will partner with EI and EHS to expand infrastructure through the state to ensure hearing screening up to age 3. Challenges often occur when there is a change in practice; in addition, we anticipate that there may be challenges with data reporting between these early childhood programs and RI-EHDI. To address data related challenges, RI will work closely with the KIDSNET IT consultant (HLN Consulting). In addition, as mentioned in the methodology section, RI plans to partner with the Early Childhood Hearing Outreach (ECHO) Initiative, which focuses on ensuring that early childhood providers understand the benefits of periodic hearing screening in a variety of health and education settings and trains early childhood providers on how to implement OAE hearing screenings for children who are between 0 and 3 years of age.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Ongoing evaluation will help to ensure that the activities implemented through this grant are related to the overarching grant goals and will be used to monitor progress towards meeting the measurable goals and objectives of the project, as outlined in this proposal. Ongoing collaboration between the evaluation team and the quality improvement team will ensure that these efforts are complimentary.

RI has created an evaluation team that includes the Newborn Screening Manager, the Newborn Hearing Screening Program Manager, Medical Director for the RI-EHDI Program the RI-EHDI Audiologist, and a member of the RI-EHDI Advisory Committee. The Newborn Screening manager will serve as the data and evaluation lead for the RI-EHDI evaluation team. The team will meet monthly to monitor progress toward reaching objectives and ensure that activities are occurring within specified time frames; team members will review data related to program processes performance, goals and objectives. The team will utilize input from the QI team, the RI-EHDI Advisory Committee as a whole, pediatricians, families and other stakeholders. Close collaboration and regular in-person meetings with partners will support ongoing evaluation, QI activities, and the early identification and responses to any concerns or technical assistance needs that arise. Evaluation updates and findings will be presented at quarterly RI-EHDI Advisory Committee meetings as well as to RIDOH leadership.

The Quality Improvement Team is led by Ellen Amore, the Principal Investigator for the CDC-EHDI Cooperative Agreement. She will provide technical support for ongoing Quality Improvement activities. The EHDI QI team will meet monthly to identify new CQI opportunities and to support ongoing CQI activities in order to meet the program goals. The group's work will be informed by ongoing data review and close collaboration with the evaluation team. Possible

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quality improvement project topics include, but are not limited to, improving strategies for re-engaging families who do not keep diagnostic appointments, supporting timeline screening for babies treated in the NICU, strategies for timely completion of audiological evaluation for all families, and reducing disparities in service access, utilization and outcomes. Additional project areas will be identified through data review and stakeholder input throughout the grant period. Quality Improvement efforts and the related data will be reviewed collaboratively with the evaluation team and will be presented at quarterly RI-EHDI Advisory Committee meetings.

Evaluation Overview:

The evaluation consists of process and outcome evaluation designed to monitor progress and inform program delivery through ongoing feedback to RI-EHDI Advisory Committee, RIDOH leadership, and the QI team as well as other stakeholders. Program activities guide the evaluation questions, process and outcome measures identified. A non-experimental mixed methods design will be used to evaluate the many aspects of program implementation, process and outcomes. Table 1 presents a broad overview organized by objectives and with additional process and outcome measures specific to each of the goals.

For quantitative analysis, the evaluation and quality improvement teams will utilize two of the state's robust data systems, RITRACK, RI's EHDI data system, and KIDSNET, RI's child health information system. Additional data will be collected and monitored as needed, including surveys and feedback from family members and other stakeholders.

Key Evaluation Questions

Throughout the project period the RI-EHDI program evaluation will use both quantitative and qualitative methods to monitor ongoing efforts and progress towards meeting the overarching goals and objectives of the project. Aspects of each of the RI specific state goals will support each of the overarching objectives. RI goals are cross cutting in impact and will support RI-EHDI to reach all objectives.

Through the use of custom reports that are built to meet the specific needs of the evaluation, the evaluation team will be able to review the data as needed throughout the course of the program and with the support of the Data and Evaluation lead, the Principal Investigator for the CDC-EHDI Cooperative Agreement, and the Newborn Screening Data Manager will be prepared to report on all measures both quarterly and annually as part of the annual progress report. The same data team will take the lead on establishing baseline data, following the completion of the first year of data collection. Once the baseline data is established the measurable SMART goals and objectives will be updated and further specified to guide the targets for the ongoing work of the RI-EHDI program throughout the grant period.

Table 1: RI-EHDI Evaluation Plan Overview

Objective 1	By March 31, 2024 the RI-EHDI Program will increase from 94 percent to 98 percent (1% each year) the percent of infants that complete a newborn hearing screening no later than 1 month of age. [Baseline from the 2017 CDC EHDI HSFS]
Supportive RI Grant Efforts	#1 Engaging all EHDI system stakeholders at the state level to improve developmental outcomes of children who are D/HH #2 Ensuring that all newborns meet the 1-3-6 recommendations and that few children are lost to follow-up/documentation

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	#5 Increasing health professionals’ knowledge of the 1-3-6 recommendations and the EHDI system
Sample Key Evaluation Questions	<ol style="list-style-type: none"> 1. To what extent did RI-EHDI activities increase the number of newborns with a timely diagnosis per JCIH standards? 2. To what extent did RI-EHDI activities, specifically collaborative activities with the PCMH-Kids group, increase provider knowledge and adherence to JCIH standards? 3. To what extent did RI-EHDI activities increase knowledge among providers on how to participate in and contribute to both the state level and community EHDI system?
Target Audience	Providers conducting OAE screening and diagnosis, families and caregivers of children who failed the Newborn Hearing Screen (NBHS)
Partners	Providers conducting OAE screening, RI-EHDI, staff at birthing hospitals where initial screening takes place, families, early childhood program staff, Primary Care Providers (PCP)s
Evaluation Design	Process and outcomes evaluation; mixed methods; non-experimental
Example Outcome Measures	<ol style="list-style-type: none"> 1. Total number of screened newborns who failed initial NBHS, who are older than one months of age, and of those: <ol style="list-style-type: none"> a) Percent of newborns who failed initial NBHS 1 or more months ago with OAE within 1 month b) Percent of newborns who failed initial NBHS 1 or more months ago with OAE beyond the recommended 1-month time frame c) Percent of newborns who failed initial NBHS 1 or more months ago with no re-screen
Example Process Measures	<ol style="list-style-type: none"> 1. Number of screened newborns who failed initial NBHS, who are still less than 1 month of age, and therefore within the recommended timeframe for hearing screening, but have not yet received a re-screen 2. Number of PCMH-Kids pediatric sites and providers participating in collaborative activities with the RI-EHDI program 3. Number of PCMH-Kids providers who report learning new information relative to the JCIH standards 4. Number of primary care providers who participated in web-based training modules 5. Number of trainings conducted with early childhood program staff on current EHDI 1:3:6 timeline recommendations, and the risk factors for later onset hearing loss
Data Sources	RITRACK database, KIDSNET database, PCMH-Kids collaborative feedback, case conference reports

Objective 2	To achieve the minimum rate by March 31, 2024 the RI-EHDI Program will increase from 59 percent to 85 percent, for the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age. [Baseline from the 2017 CDC EHDI HSFS]
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Supportive RI Grant Efforts	#1 Engaging all EHDI system stakeholders at the state level to improve developmental outcomes of children who are D/HH #2 Ensuring that all children meet the 1-3-6 recommendations and that few children are lost to follow-up/documentation #5 Increasing health professionals’ knowledge of the 1-3-6 recommendations and the EHDI system
Sample Key Evaluation Questions	1. To what extent did RI-EHDI activities increase the number of infants with a timely diagnosis per JCIH state wide? 2. To what extent did RI-EHDI activities increase the number of infants with a timely diagnosis per JCIH among PCMH-Kids sites? 3. To what extent did RI-EHDI educational activities increase provider knowledge and adherence to JCIH standards? 4. To what extent did RI-EHDI activities increase knowledge among providers on how to participate in and contribute to both the state level and community EHDI system?
Target Audience	Providers conducting OAE screening and diagnostic assessments, families and caregivers of children who failed the initial NBHS
Partners	Providers conducting OAE screening, RI-EHDI, staff at birthing hospitals where initial screening takes place, families, RIPIN, other early childhood program staff
Evaluation design	Process and outcomes evaluation; mixed methods; non-experimental
Example Outcome Measures	1. Total number of screened newborns who failed initial NBHS, who are older than three months of age, and of those: a) Percent of newborns who failed initial NBHS 3 or more months ago within 3 months b) Percent of newborns who failed initial NBHS 3 or more months ago beyond the recommended 3-month time frame c) Percent of newborns who failed initial NBHS 3 or more months ago with no diagnosis
Example Process Measures	1. Number of screened newborns who failed initial NBHS, who are still less than three months of age, and therefore within the recommended timeframe for diagnosis, but have not yet received a diagnosis 2. Number of PCMH Kids Providers who report learning new information relative to the JCIH standards 3. Number of trainings conducted with other early childhood programs on current EHDI 1:3:6 timeline recommendations, and the risk factors for later onset hearing loss
Data Sources	RITRACK database, PCMH-Kids collaborative feedback, KIDSNET database, case conference reports
Objective 3	To achieve the minimum rate by March 31, 2024 the RI-EHDI Program will increase from 40 percent to 80%, the number of infants identified to be D/HH that are enrolled in Early Intervention services no later than 6 months of age. [Baseline from the 2017 CDC EHDI HSFS]

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Supportive RI Grant Efforts	#1 Engaging all EHDI system stakeholders at the state level to improve developmental outcomes of children who are D/HH #2 Ensuring that all children meet the 1-3-6 recommendations and that few children are lost to follow-up/documentation #5 Increasing health professionals' knowledge of the 1-3-6 recommendations and the EHDI system
Sample Key Evaluation Questions	1. To what extent did RI-EHDI activities, specifically coordination of referrals through the Parent Resource Specialists, increase the number of infants with a timely referral to EI per JCIH guidelines? 2. To what extent did RI-EHDI activities identify and respond to any barriers in the evaluation and referral process?
Target Audience	EI programs and staff, families, RI's EHDI parent consultant
Partners	PRS, audiologists, EI, EI CoP, families, RIPIN, medical home providers, other early childhood programs and staff
Evaluation design	Process and outcomes evaluation; mixed methods; non-experimental
Example Outcome Measures	1. Number of infants diagnosed with confirmed hearing loss 2. Percentage of infants diagnosed with confirmed hearing loss referred to EI per JCIH recommended practice 3. Percentage of infants diagnosed with confirmed hearing loss referred to EI past JCIH recommended milestone 4. Percentage of infants diagnosed with confirmed hearing loss, who are lost to follow-up, prior to enrollment in EI
Example Process Measures	1. Percentage of infants diagnosed with confirmed hearing loss, who are lost to follow-up, prior to EI enrollment 2. Number of joint meetings between PRS, families and audiologists to initiate referral for children newly diagnosed with hearing loss 3. Number of families for whom the PRS coordinates with the medical home 4. Number of audiologists participating in the educational activities
Data Sources	RITRACK database, KIDSNET database, learning collaborative database, additional data provided by PRS, additional data from EI as needed

Objective 4	By March 31, 2024 the RI-EHDI Program will increase by 20% from baseline, the number of families enrolled in family-to-family support services by no later than 6 months of age. Baseline to be established using data collected during year 1.
Supportive RI Grant Efforts	#2 Ensuring that all newborns meet the 1-3-6 recommendations and that few children are lost to follow-up/documentation #3 Expanding state capacity to support hearing screening in young children up to 3 years of age #4 Improving family engagement, partnership, and leadership within the EHDI programs and systems
Sample Key	1. To what extent did RI-EHDI activities, specifically coordination of referrals through the parent consultant, increase the number of families enrolled in family-to-family support services?

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Evaluation Questions	2. To what extent did RI-EHDI activities ensure access to high quality, culturally competent Early Intervention?
Target Audience	PRS, EI staff, Families, H&V
Partners	PRS, families, audiologists, EI staff; parent subcommittee, H&V
Example Outcome Measures	<ol style="list-style-type: none"> 1. Number of families enrolled in family-to-family support services 2. Percent of families of a newborn diagnosed with confirmed hearing loss enrolled in a family-to-family support service by 6 months of age 3. Percent of families of a newborn diagnosed with confirmed hearing loss enrolled in a family-to-family support service after 6 months of age
Example Process Measures	<ol style="list-style-type: none"> 1. Percentage of infants diagnosed with confirmed hearing loss lost to follow up prior to enrollment of family-to-family support service 2. Number of joint meetings between RI’s EHDI parent consultant, families and EI to initiate referral for children newly diagnosed with hearing loss 3. Number of families for whom the parent consultant coordinates with EI 4. Number of families participating in family-to-family support service 5. Number of families that have partnered with H&V for peer to peer support
Data Sources	RITRACK database, KIDSNET database, learning collaborative database, learning collaborative feedback, case conference reports and EHDI stakeholders

Objective 5	By March 31, 2024 the RI-EHDI Program will increase by 10% from baseline, the number of families enrolled in D/HH adult-to-family support services by no later than 9 months of age. Baseline to be established using data collected during year 1.
Supportive RI Grant Efforts	<p>#1 Engaging all EHDI system stakeholders at the state level to improve developmental outcomes of children who are D/HH</p> <p>#4 Improving family engagement, partnership, and leadership within the EHDI programs and systems</p>
Sample Key Evaluation Questions	<ol style="list-style-type: none"> 1. To what extent did RI-EHDI activities, specifically coordination of referrals through the PRS, increase the number of families enrolled in D/HH adult-to-family support services? 2. To what extent did RI-EHDI activities increase the number of families enrolled in D/HH adult-to-family support services? 3. To what extent did RI-EHDI activities increase the number of families enrolled in D/HH adult-to-family support services by 9 months of age?
Target Audience	EI programs and staff, families, RIPIN, Gallaudet University, RI H&V
Partners	Families, audiologists, EI, Advisory Committee parent subcommittee, H&V, RIPIN
Example Outcome Measures	<ol style="list-style-type: none"> 1. Percentage of infants diagnosed with hearing loss referred to adult-to-family support services per JCIH recommended practice 2. Percentage of infants diagnosed with hearing loss enrolled in adult-to-family support services by 9 months

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	<ol style="list-style-type: none"> 3. Percentage of families participating in adult-to-family support services who report satisfaction with the quality and capacity of adult-to-family support services to meet the needs of the child who is deaf or hard of hearing 4. Percent of families of a child diagnosed with hearing loss enrolled in adult-to-family support services
Example Process Measures	<ol style="list-style-type: none"> 1. Number of children referred to adult-to-family support services 2. Number of children who have are not enrolled adult-to-family support services 3. Number of joint meetings between PRS, families and EI to initiate referrals for children newly diagnosed with hearing loss for adult-to-family support services
Data Sources	RITRACK database, KIDSNET database, annual family feedback, focus group feedback, case conference reports

Objective 6	By March 31, 2024 the RI-EHDI Program will increase by 10% from baseline, the number of health professionals and service providers trained on key aspects of the EHDI program. Baseline to be established using data collected during year 1.
Supportive RI Grant Efforts	<ol style="list-style-type: none"> #1 Engaging all EHDI system stakeholders at the state level to improve developmental outcomes of children who are D/HH #5 Increasing health professionals’ knowledge of the 1-3-6 recommendations and the EHDI system
Sample Key Evaluation Questions	<ol style="list-style-type: none"> 1. To what extent did RI-EHDI activities, increase the number of trained health professionals and service providers on the key aspects of the EHDI program? 2. To what extent did RI-EHDI activities increase the number of health professionals and service providers knowledge and adherence to JCIH standards?
Target Audience	EHDI team, Primary Care Providers, Audiologists, EI, Early Childhood programs, families
Partners	EHDI team, RIPIN, audiologists, EI, PCMH-Kids, families, EI service providers, other early childhood programs and staff
Example Outcome Measures	<ol style="list-style-type: none"> 1. Number of PCMH Kids providers who report learning new information relative to the JCIH standards 2. Number of PCMH Kids providers who can identify their role in the state and community EHDI system
Example Process Measures	<ol style="list-style-type: none"> 1. Number of partnerships with family-based organizations 2. Number of opportunities for families of children who are deaf or hard of hearing to participate in policy development and systems design 3. Number of families who participate in policy development and systems design of the EDHI system 4. Number of meetings of the Advisory Committee with family participation 5. Number of joint meetings between PRS, families and audiologists to initiate referral for children newly diagnosed with hearing loss
Data Sources	KIDSNET, focus group data

Data management system

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For quantitative analysis the evaluation and quality improvement teams will utilize two of the state's robust data systems, RITRACK, the RI-EHDI data system, and KIDSNET, RI's child health information system. RITRACK is a custom designed newborn hearing screening database developed in Microsoft Access. RITRACK follows all births through screening to referral for diagnostic audiology and enrollment in EI. RITRACK is integrated with KIDSNET, a population based integrated child health information system that facilitates the collection and appropriate sharing of preventive health services data for the provision of timely and appropriate follow-up.

Selected data are integrated with other child health data in KIDSNET. This integration facilitates collection and appropriate sharing of RI-EHDI data. KIDSNET will be used to develop reports which are customized to meet the needs of the evaluation and can be run as needed throughout the course of the program. KIDSNET is organizationally located in CHDA at RIDOH. CHDA has extensive capacity to support data collection and analysis and will support the evaluation efforts in this proposal. Data is collected and entered into KIDSNET through both data transfer files and by community partners who have been given access to KIDSNET through a web portal. The data is managed by a KIDSNET data manager who dedicates 20% of his time to working on Newborn Screening including Newborn Hearing Screening. As outlined in the following description additional quantitative and qualitative data measures will also be established and collected.

Technical Capacity and Support

The leadership and advisory entities involved with this project have extensive experience with grant related work for the Newborn Hearing Screening Program, as well as similar programs. The PECH Team Lead will help to support the evaluation work and has over 15 years of experience in data analysis and evaluation. The EHDI Medical Director will also closely support evaluation efforts and has extensive experience in primary research and related evaluation. CHDA will also support the work, when appropriate. In addition, the Newborn Screening Manager has extensive experience in CQI, has been trained on both the Model for Improvement and the Lean Model methods of CQI, and has participated in multiple Kaizen CQI Improvement Events.

By using a mixed-methods evaluation design, supported by and in support on continuous quality improvement efforts, the RI-EHDI program will be able to monitor progress towards the overarching goals of the program and process outcomes tied to the specific program goals. Specifically, the evaluation aims to determine if activities implemented through this grant were successful in engaging providers to support a comprehensive system of care, reducing the loss to follow-up rate, getting infants into services at the earliest possible opportunity and meeting the needs of infants and families.

Data reporting process

A daily file containing individual level demographic data is downloaded from the electronic birth certificate to create new records in KIDSNET. KIDSNET sends daily files of new official Rhode Island births to RITRACK, thus making it possible to identify infants at the individual level who were not screened, passed the screen, or did not pass (including inpatient/initial screens and outpatient/rescreens).

Also included in that file are address, phone, primary care provider, and race/ethnicity information. Individual level screening data, including both inpatient/initial screens and outpatient/rescreens are downloaded daily electronically directly from screening equipment in the hospitals into RITRACK. Additional information that cannot yet be imported electronically

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are data entered. If an outpatient rescreen is completed by an audiologist, it may be reported on paper for data entry into RITRACK. RITRACK generates reminders of follow-up needs to families and medical homes, and tracks services. Audiologists report diagnostic data on-line through KIDSNET or via paper or fax to RI-EHDI where staff data enter it into RITRACK. EI data, collected centrally at the state level from EI sites, are imported bimonthly to KIDSNET from the EI data system.

RITRACK can generate many data reports, including what is needed to complete the annual CDC EHDI Hearing Screening and Follow-up Survey (HSFS). Rhode Island is currently in the process of integrating the functionality of RITRACK into KIDSNET. The CDC funding for EHDI activities provide significant support for data support, infrastructure and linkages. As part of the plan to expand infrastructure for data collection and data reporting, the EHDI program is currently exploring electronic transfer of diagnostic data from large hospital-based audiology departments. This systems integration along with data extraction from EHS agencies, will enhance the plan to expand the infrastructure for data.

Potential obstacles for implementing the program performance evaluation and plan to address

Some potential obstacles to collecting data for the program performance evaluation include the following:

1) Matching and synchronizing data: Records from the electronic birth certificate system, KIDSNET, RITRACK, and EI data systems must be matched daily and synchronized to assure that all infants born in RI receive newborn hearing screening and appropriate follow-up, including EI for children with permanent hearing loss. Although matching is automated, the matching and synchronization of systems involves significant manual intervention. As mentioned above, RI is currently in the process of integrating the functionality of RITRACK into KIDSNET. This will improve the efficiency and reduce errors and delays associated with data transfer.

2) EI: Due to federal privacy laws (FERPA), consent is required by EI before data about EI enrollment can be sent to KIDSNET. Collection of EI enrollment data can be impacted for several reasons including: a) EI internal policies and procedures that delay the data entry of IFSP dates, and b) FERPA which prohibits sharing information without parent authorization. Currently, RI-EHDI complies with FERPA by collecting parent consent to share information between RI-EHDI and EI through an EHDI authorization form, which the PRS is responsible for getting signed. However, the PRS face challenges when they are unable to schedule a home visit to obtain the authorization form signed. To address this issue, RI-EHDI will work with EI on how the service provider working with the family can collect the signed consent. In addition, by participating in the EI CoP, the EHDI program will continue to educate, train, and provide resources to those working with D/HH children between the ages of birth to three.

3) Audiology reporting: Although diagnostic audiology results can be reported by on-line data entry, fax, or paper, these manual methods are labor intensive and remain a barrier to complete and consistent reporting by audiologists. Therefore, the EHDI team is also working on a project to try to extract data directly from the electronic medical records used at Women and Infants and Hasbro Hospitals.

4) Aging system: RITRACK was developed in the 1990s when the focus was on screening all infants. It has grown over the years to accommodate new tracking requirements but is limited. RI is currently in the process of integrating the functionality of RITRACK into KIDSNET.

ORGANIZATIONAL INFORMATION

The mission of RIDOH is to prevent disease and to protect and promote the health and safety of the people of Rhode Island. RIDOH coordinates public health activities across the state. RIDOH is located within the state Executive Office of Health and Human Services (EOHHS), a cabinet agency that directly reports to the Governor. RIDOH has six Divisions. RI-EHDI is located in the Division of Community Health & Equity (DCHE), which is in the Center for Perinatal and Early Childhood Health (PECH) (Attachment 5). The DCHE's mission is to eliminate health disparities and promote health equity, prevent and control disease and disability, and support early childhood development. The PECH Center is responsible for supporting healthy birth outcomes, positive early childhood development, and school readiness in preparation for a healthy, productive adulthood by assuring mothers and children have access to quality Maternal and Child Health services. The Team has the following areas: Newborn Screening & Follow-Up, Early Childhood Systems Initiatives, WIC, and Home Visiting.

Placing the RI-EHDI Program within the PECH Center was intentional; it ensures that the newborn screening system is part of an overall system of services for pregnant women and families with young children. Locating RI-EHDI within the PECH Center supports better alignment of programs and policies for maternal and child health programs. It also ensures that the personnel with the appropriate education and experience are able to support program activities and that systems level outcomes and objectives are achieved. Programs outside of the PECH Center, but within RIDOH, also support early childhood systems work; these include KIDSNET, Title V, Children and Youth with Special Health Care Needs, Family Planning, and Immunization.

Experience since 2004 has highlighted the importance of leadership to successfully implement and sustain RI-EHDI. The Medical Director of RIDOH's Division of Community Health and Equity is a pediatrician. In this role she participates in many early childhood systems decisions around programming, policy, leadership and funding. Dr. Blythe Berger who is the Chief of the PECH Center, is also the Title V Policy Advisor and helps guide the vision and integration of Maternal and Child Health (MCH) programs. Dr. Berger also serves on the Early Learning Council, the RI-EHDI Advisory Committee, and the Home Visiting Interdepartmental Management team; all of these are interdepartmental initiatives that integrate systems at both the state and community level. RIDOH staff are influential at multiple levels of the MCH and early childhood system, providing input into policies and practices, providing data to support decision making and disseminating best practices at the state and national level. Liza Then is the RI-EHDI Coordinator. Ms. Then is responsible for the planning, coordinating and administering of RI-EHDI. She supports the ongoing implementation of RI-EHDI activities and supports data collection to meet program requirements and ongoing CQI activities. She will oversee the daily operations of the project, manage contracts and project budgets, and collaborate with internal staff as well relevant community agencies and partners to implement the project work plan.

Emily Eisenstein is the Data Evaluation Manager and CQI specialist; she will plan, organize, direct and review the activities related to collecting, assembling, analyzing, processing and interpreting EHDI data and related information. She will provide technical assistance for the EHDI program staff and supports the implementation of continuous quality improvement activities and performance monitoring.

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As mentioned throughout the document, RIDOH has extensive community supports through partnerships with RIPIN and agencies providing WIC, EI, EHS, Family Home Visiting and other services. Along with community supports, the RI-EHDI team and the larger team at RIDOH works with other state agencies including the Executive Office of Health and Human Services, which houses EI, the RI Department of Education, DCYF, and the RI Department of Human Services. Finally, as noted in the methodology and workplan, the RI-EHDI program plans to work with both regional and national technical assistance providers.

The missions, structures, and scope of activities of RIDOH and the Division of Community Health and Equity significantly contribute to the RI-EHDI program's ability to conduct program requirements and to meet program expectations in several ways.

Discuss how the organization will follow the approved plan, as outlined in your application, properly account for the federal funds, and document all costs to avoid audit findings.

The RIDOH has implemented timekeeping systems to assure that all salary and fringe charges to federal funding sources reflect actual work performed. Due to the State of Rhode Island's antiquated payroll system, salary and fringe initially are charged based on the estimated level of effort per the proposed budget, but each staff member tracks hours actually worked for all the programs and/or activities to which they are assigned. The budgeted estimates are compared to the actual time worked, and salary and fringe charges are reconciled to reflect actual effort not less than quarterly.

Ms. Then, with support from the Fiscal Operations team at RIDOH, will be responsible for all fiscal components of the program including budget development and implementation, obligation of funds, and expenditure tracking, including the documentation of all federal costs to avoid audits. Ms. Then and the Fiscal Operations team liaison to the PECH team will meet formally on a monthly basis to review spending and will meet informally as needed. The Fiscal Operations team will be responsible, with assistance from Ms. Then, in submission of federal financial reports. The PECH team has a great deal of experience managing the fiscal side of federal grants and has a robust system in place.

How unique needs of target population of communities served are routinely assessed/improved

RI routinely updates and reviews both relevant data and multiple needs assessments, such as those for Title V and Family Home Visiting, on a regular basis. RIDOH staff attend both the Early Intervention ICC Interagency Coordinating Council and Local Implementation Teams. The MCH and early childhood systems efforts supplement the information gained from needs assessments with other valuable sources of information including the Title V Maternal and Child Health Needs Assessment and the Pregnancy Risk Assessment Monitoring System (PRAMS) data. As can be seen from the documented relationships between the EHDI program and other entities, RIDOH has broad support to develop and improve its system. Representatives participate on the EHDI Advisory Committee, work to align strategic plans, jointly participate on the Commission for Deaf and Hard of Hearing, and have worked together to support shared data systems. Most of the required partners for this work are already in place and committed to the work, including representatives from the birthing hospitals, audiologists, Title V, RIPIN, EI, The Commission for the Deaf of Hard and Hearing, Family Home Visiting, WIC, LEND, the EI-ICC Interagency Coordinating Council, Title V, and pediatricians in private practice and health centers.

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Ability to facilitate partnerships with and engage families, health professionals, and service providers.

RIDOH has a long history of engaging families, health professionals, and service providers, which is described previously in this proposal. The DCHE and MCH/Title V programs are deeply committed to incorporating the perspectives of families, health professionals, and service providers into all systems, policy, and program development work. RIDOH has strong leadership from primary care providers, including multiple physicians on staff, which facilitates engagement with this group. RIDOH staff are currently involved in other related projects with Community Health Centers and pediatricians, including the PCMH-Kids Initiative. In addition, RIDOH has maintained long partnerships with parent support organizations and has a history of ensuring that parents participate in program and policy development. The Family Home Visiting Team recently developed a Parent/Caregiver Advisory Council, which will be used to guide program development for Family Visiting and other programs within the PECH program. There are currently multiple parent consultants working at RIDOH, of which, the RI-EHDI program supports 2. These strong existing relationships within RIDOH as well as those established in communities, facilitates the ability of the RI-EHDI program to collaborate with parents and providers (both medical and service) on work to improve the systems that serve children who are deaf and hard of hearing and their families to have positive outcomes.

The Rhode Island Universal Newborn Hearing Screening program is thrilled for this funding opportunity to reconsider our focus and direction for the upcoming four years and contemplate emerging issues impacting the children identified deaf or hard of hearing. As the RI Universal Newborn Hearing Screening program is responsible for ensuring that all initiatives towards EHDI throughout the state are accomplished, are coordinated, is a family centered system of care for families of children D/HH. We will continue to do so while advising RI-EHDI's priorities to support families with newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing (D/HH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI).

ⁱ Rhode Island Department of Health (2014). KIDSNET data. Center for Health Data and Analysis.

ⁱⁱ Joint Committee on Infant Hearing (2007). Year 2007 Position Statement: Principles and guidelines for Early Hearing detection and Intervention Programs. *American Academy of Pediatrics*, 120(4) 898-915.
Doi:10.1542/peds.2007-2333

ⁱⁱⁱ Rhode Island KIDSCOUNT (2018). *2018 Rhode Island KIDSCOUNT Factbook*. Providence, RI. Retrieved from: <http://www.rikidscount.org/Portals/0/Uploads/Documents/Factbook%202018/2018%20Factbook.pdf>

^{iv} Rhode Island Department of Health (2019). KIDSNET data. Center for Health Data and Analysis.

^v Rhode Island Department of Health (2017). KIDSNET data. Center for Health Data and Analysis.

^{vi} Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*. 2013;131(4):e1324-e1349

^{vii} Abreu, R., Adriático, T., & DePierro, A. (2011). Qué pasa?: "What's happening" in overcoming barriers to serving bilingual children? *The ASHA Leader*

^{viii} Rhode Island KIDSCOUNT (2019). *2019 Rhode Island KIDSCOUNT Factbook*. Providence, RI. Retrieved from:

<http://www.rikidscount.org/Portals/0/Uploads/Documents/Factbook%202019/2019%20FACTBOOK%20FINAL.pdf>

^{ix} Centers for Disease Control and Intervention. Plans for State Oral Health Programs and Activities. Retrieved October 25, 2019 from https://www.cdc.gov/oralhealth/state_programs/infrastructure/plan.htm

PROJECT NARRATIVE

- x Rhode Island Department of Health and Rhode Island Oral Health Commission. (2017). Rhode Island Oral Health Plan, 2017 – 2021.
- xi Department of Health and Human Services Substance Abuse and Mental Health Services Administration FY 2019 Linking Actions for Unmet Needs in Children’s Health Grant Program Short Title: Project LAUNCH (Modified Announcement) Funding Opportunity Announcement (FOA) No. SM-19-007 Catalogue of Federal Domestic Assistance (CFDA) No.: 93.243 https://www.samhsa.gov/sites/default/files/grants/pdf/sm-19-007_project_launch.final_02-22-19.pdf
- xii U.S. Department of Health and Human Services Office of Minority Health. The National CLAS Standards. Retrieved from: <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53>
- xiii National Center for Hearing Assessment and Management (NCHAM) at Utah State University (2015). Early Hearing Detection and Intervention Website Resource Guide. Retrieved from: <https://www.infanthearing.org/webguide/index.html>
- xiv NCHAM at Utah State University (2015). The NCHAM eBook: A resource guide for Early Hearing Detection and Intervention (EHDI). Retrieved from: http://www.infanthearing.org/ehdi-ebook/2015_ebook/35-Chapter35Financing2015.pdf
- xv http://www.infanthearing.org/ehdi-ebook/2015_ebook/35-Chapter35Financing2015.pdf
- xvi Flanagan, P. & Lange, B. (2019). Welcome 2019 PCMH Kids Expansion Practices [PowerPoint Slides]. Retrieved from <https://www.ctc-ri.org/sites/default/files/uploads/Welcome%20from%20Pat%20%20Beth.pdf>
- xvii Ward, A., Hunting, V., & Behl, D. (2018). Needs Assessment Report: Family Leadership in Language and Learning (FL3). Retrieved from: https://www.handsandvoices.org/fl3/resources/docs/HV-FL3_NeedsAssessment_19Jul2018_Final-opt.pdf
- xviii Ward, A., Hunting, V. https://www.handsandvoices.org/fl3/resources/docs/HV-FL3_NeedsAssessment_19Jul2018_Final-opt.pdf
- xix National Center for Medical Home Implementation and the National Academy for State Health Policy. (2016). Shared Plan of Care: A tool to support children and youth with special health care needs and their families. Retrieved from: <https://medicalhomeinfo.aap.org/tools-resources/Documents/Shared%20Plan%20of%20Care2.pdf>
- xx Hanna, C., DesGeorges, J., & Forsman, I. (2010). Improving Follow-up to Newborn Hearing Screening: A Learning-Collaborative Experience. *Pediatrics* 126(S59). doi:10.1542/peds.2010-0354K
- xxi Watkins, S., Pittman, P., & Walden, B. (1998). The Deaf Mentor Experimental Project for young children who are deaf and their families. *American Annals of the Deaf* 143(1), 29-34. Doi:10.1353/aad.2012.0098
- xxii Family Leadership in Language and Learning (2018). Needs Assessment Report. Retrieved from: https://www.handsandvoices.org/fl3/resources/docs/HV-FL3_NeedsAssessment_19Jul2018_Finalopt.pdf
- xxiii SKI HI Institute. Deaf Mentor Program. Retrieved from: <http://www.deaf-mentor.skihi.org/>
- xxiv Early Hearing and Detection and Intervention Act of 2017, Public Health Service Act, Title III, Section 399M (as added by P.L. 106-310, Sec. 702; as amended by P.L. 111-337 and P.L. 115-71. Retrieved from: <https://www.congress.gov/115/plaws/publ71/PLAW-115publ71.pdf>