Ajiri in Ibwinini

PROJECT NARRATIVE

INTRODUCTION

The Republic of the Marshall Islands (RMI), politically linked with the United States, was the last such nation in the Pacific region to develop a program of newborn hearing screening. The geographic challenges presented by the RMI are probably the most formidable of any place that has attempted to implement universal newborn hearing screening. However, emergence of other programs in the Pacific Islands, and the developing resources of the region, encouraged the RMI to first submit in 2009 an application for funding for a newborn hearing screening program. The RMI is currently in the third year of a three-year HRSA grant—*Ajiri in Ibwinini,* meaning "our most precious children." Based on the initial successes of the HRSA grant, a surveillance grant entitled, "Identify and Follow: *Ajiri in Ibwinini,"* was submitted and funded.

During the first year of the HRSA grant, the RMI contracted a significant portion of funds to the Center on Disability Studies at the University of Hawaii for technical support and evaluation, including contracting for outside consultants. Although it took six months for that contract to be finalized, the arrangement worked well, enabling the RMI to meet its 1-3-6 objectives in the first year of the grant. This included providing audiological evaluations within a month of birth, and entering children into early intervention services within a week of diagnosis. However, during the second year of that grant, no contract could be finalized and to date in the third year, no contract has been finalized. Due to bureaucratic hurdles, newborn nursery screening ceased in mid-February of 2012. Although three years of funding was allotted, less than [redacted] has yet been spent by the program. To address those bureaucratic issues, the RMI Min-

istry of Health has requested the Center on Disability Studies at the University of Hawaii (CDS-UH) to apply to administer a grant on their behalf for this next three-year cycle of funding.

Because RMI is far removed from the mainland United States and so unusual in its geography and resource capacity, an extensive description of RMI will be presented in the Needs Assessment section to enable reviewers to better understand the challenges that exist in the implementation of newborn hearing screening in a very remote, rural location.

NEEDS ASSESSMENT

The Republic of the Marshall Islands' location at such a great distance from the mainland United States presents great geographic and resource challenges to implement a successful newborn hearing screening program. Yet, the needs of the people drive a strong commitment from competent local personnel who are working very hard to make this program a reality. Remaining largely unmet are the needs for the target population of newborns and young children with a significant permanent hearing loss to develop communication and academic skills commensurate with their hearing counterparts. The combination of the economy, major health challenges, service limitations for children with hearing loss, EDHI programs, health services, transportation, educational services, as well as their history and political status contribute to the dire need for providing services with newborn hearing screenings. Geographic, resource, and bureaucratic barriers remain as will be shown in subsequent sections. The needs are great, the challenges, enormous, but the opportunity is auspicious and must be grasped!

Colonial History

The Spanish were the first Europeans to sail into and explore the islands, with at least seven Spanish ships visiting during the 16th century. The British arrived later, in the persons of two ship captains named Marshall and Gilbert. Following the fashion of British explorers to rename their "discoveries," Marshall renamed the islands after himself. A nearby group of islands

was renamed "Gilbert." American missionaries arrived in the Marshalls in 1857 by way of Honolulu. Germans established a trading post on Ebon Atoll in the 1850s and declared the islands a German protectorate in 1885. Japan took possession from Germany in October 1914. In 1922, the League of Nations officially awarded the Marshalls to Japan as a Class C mandate. However, Japan withdrew from the League of Nations in 1933 and began militarily fortifying the atolls of Kwajalein, Wotje, Maloelap, Jaluit, and later Mili and Enewetak.

During World War II, after heavy fighting in the region, the United States defeated the Japanese, took over the islands, and the US Navy began governing the Marshalls. In 1947, the United Nations assigned the islands to the United States as a Strategic Trust. In 1951, the Department of the Interior took over administration of the Marshall Islands, and they became one of the six jurisdictions of the Trust Territory of the Pacific Islands.

Between 1946 and 1954, the United States conducted 67 nuclear tests in, above, and around Bikini and Enewetak Atolls. The resulting destruction of land and exposure of the population to radiation continue to be issues of contention between the Marshallese and the United States. There are growing concerns about the epidemic of cancers that islanders believe were caused by the radiation exposure. Tensions continue today regarding adequate compensation for radiation victims.

Current Political Status

In the late 1970s, a growing desire for self-determination led the Marshalls to move towards independence. The country became independent in 1979, and, in 1986, the RMI became a parliamentary democracy with a Compact of Free Association with the United States. The Compact was renewed in 2003 for an additional 20 years. This Compact provides substantial econom-

ic aid to the country, as well as eligibility for some US federal programs. The Compact also allows RMI citizens to emigrate to the U.S. without visas.

Description of the RMI

The People. The total population of the RMI is estimated at 53,763. More than 50% of the population is under 15 years of age. The average growth rate is 3.6%, the highest in the Pacific. More than 60% of the population resides in the two urban centers (Majuro and Ebeye). The remaining 40% reside on the outer islands. The people in RMI are called Marshallese, and are of Micronesian origin. The matrilineal culture revolves around a complex system of clans and lineages tied to land ownership. The RMI is an extremely homogenous ethnic environment with Marshallese making up 95% of the population..

Economy. With a gross per capita income of [redacted], the majority of the population in the RMI lives below the federal poverty level. The RMI government is the largest employer in the country. The RMI has a developing agrarian and service-oriented economy. Income on the outer islands is generated primarily from the sale of copra (dried coconut) and handicrafts.

Transportation. Majuro and Ebeye do not have publicly financed transportation systems. Instead, people share taxis that cruise the streets until hailed by passengers. People travel from Majuro and Ebeye to the outer islands on a 24-seat Dash 8 aircraft managed by Air Marshall Islands. This aircraft is frequently inoperable making the outer islands inaccessible. Government field-trip ships travel to each outer island every two or three months, bringing passengers, medical and educational supplies, and trade goods. During low tides, people can walk on the exposed coral reefs between the islands to reach airstrips. Traveling by ship from Majuro to the most distant island takes more than 24 hours; by air, the journey takes more than 90 minutes.

Location and Geography. The RMI is located about 7,500 miles west of Washington, DC, across the International Date Line. The island nation consists of 29 atolls and 5 major islands located in two parallel groups, the "Ratak" (sunrise chain) and the "Ralik" (sunset chain). The total number of atolls, islands, and islets (small islands) is about 1,225, spread over 750,000 square miles of ocean. The total land area is about the size of Washington, DC. Each atoll consists of the atoll and a ring of islands and islets encircling a deep-water lagoon. A coral reef surrounds and interconnects each atoll and its islets. Two of the atolls – Majuro and Kwajalein – have become crowded urban centers; the other atolls and islands remain rural and are usually referred to as "outer islands." Figure 1 is a map showing the location of the RMI.

Figure 1. Map Showing Relationship of RMI to United States, Asia, Pacific, and Australia

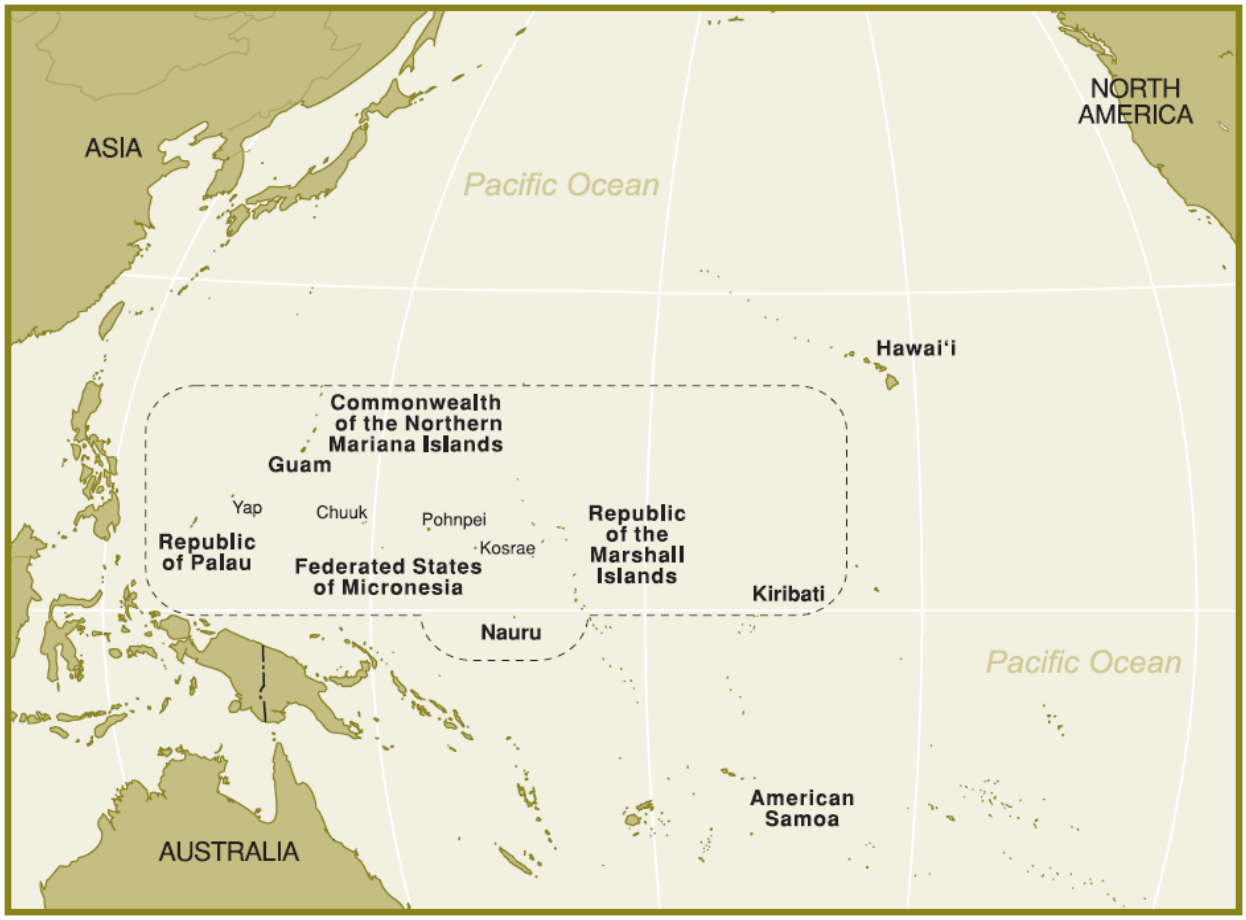
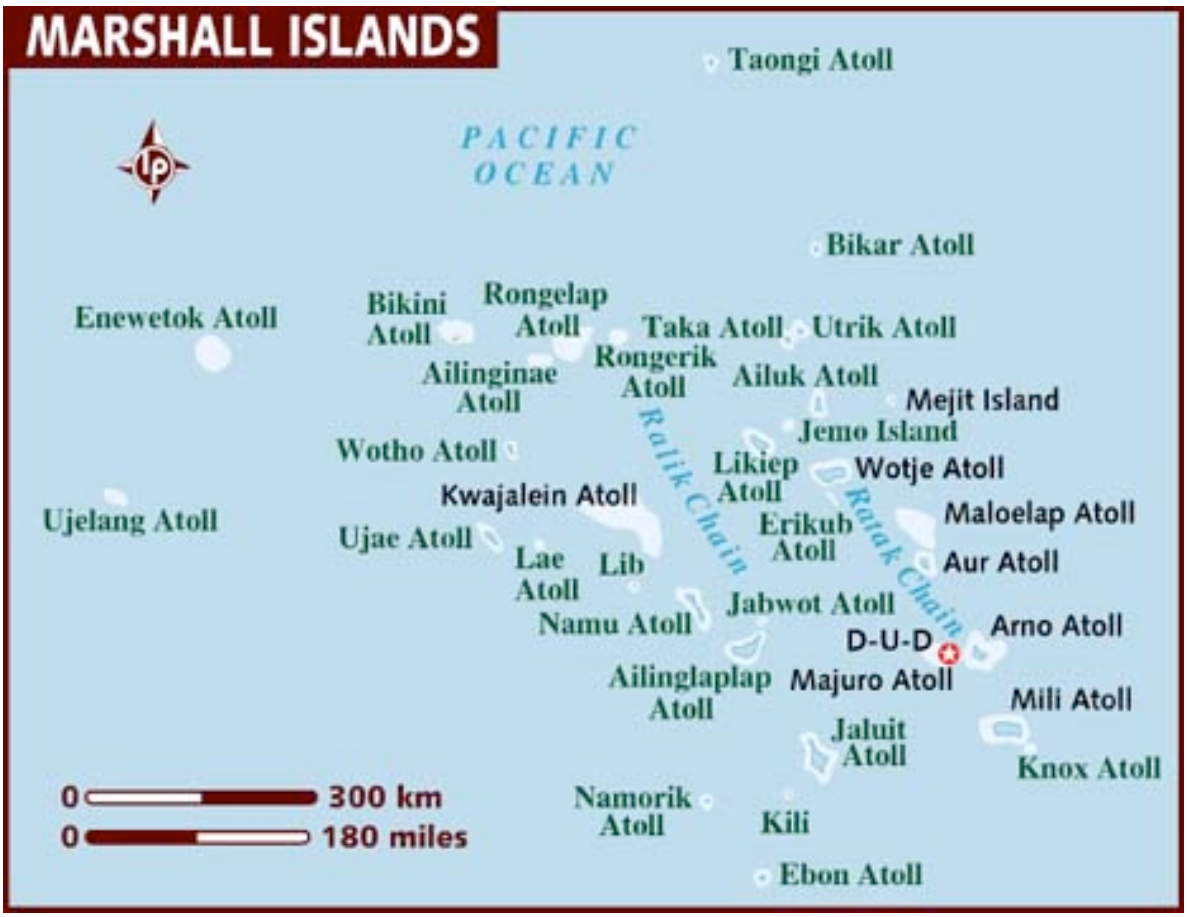


Figure 2 shows details of the atolls within the RMI. The climate is hot and humid, with a rainy season from May to November. The islands are occasionally hit by typhoons. Additionally, because none of these low-lying land areas has an elevation higher than ten feet above sea level, the RMI is at risk of flooding caused by global warming. In 2009, high tides and large ocean waves caused extensive damage to populated areas of the RMI.

Majuro is the capital of the RMI. The shape of this atoll resembles a horse shoe, with the lagoon inside. At its widest point, Majuro Atoll measures about half a mile from ocean to lagoon. As the nation's capital, it is the site of most public, commercial, and industrial development. With a land area of 3.75 square miles, Majuro Atoll has a population of 29,488.

Figure 2. Map of the Republic of the Marshall Islands



Majuro Atoll is the most highly developed area in the nation and has several high schools, a community college, a 110-bed hospital and a developing infrastructure of electrical distribution, fresh water reservoirs, and sewage disposal. The atoll is thirty miles long

Ebeye, a small island within Kwajalein Atoll (the world's largest atoll), is the only other urban center in the RMI. The urbanization of Ebeye began in the 1940s when the U.S. relocated Marshallese people who would be harmed by the US Nuclear Testing program. The population of Ebeye has grown over the years, partly because of its high birth rate, and partly because Marshallese from throughout the islands are attracted by job opportunities at the US Army base on Kwajalein. More than 11,000 people reside on a land area of .12 square miles. Housing is substandard and extremely crowded, with an inadequate water supply system. Most residents live in poverty.

The rural outer islands comprise the remainder of the RMI. Scattered over great expanses of the Pacific, population in separate communities ranges from 50 to 800 persons. Each of the 24 inhabited outer islands has an airstrip.

Health Indicators and Resources

Births. Table 1 shows annual births by place of birth. The peak birth-months are October-December. The only out-of-hospital births occur on the outer islands.

Table 1. Births in the Marshall Islands by Year and Location.

Year	Majuro Hospital	Ebeye Hospital	Outer Islands	Total by Year
2005	1,136	360	129	1,625
2006	1,013	391	164	1,568
2007	1,000	375	216	1,591
2008	1,015	345	166	1,526
2009	1,030	383	190	1,603
2010	946	311	172	1,429
2011	969	336	81	1,387

The birth data show a fairly steady decline in the number of births since 2005. It is difficult to interpret this, because many of the Marshallese have been moving to Hawaii or the U.S. mainland to seek improved employment, educational, and medical opportunities. Another interested facet of the birth statistics—Marshall Islands babies have become a source for adoption my many parents in the United States. It is difficult to obtain the number of birth adoptions, but it has become familiar in Majuro to see Caucasian women staying for the requisite period of time on the island with their adopted baby.

Majuro has a 101-bed hospital; Ebeye a 45-bed hospital. In March 2009, the Department of the Interior announced plans for the U.S. to build new 120-bed hospital for Majuro, demolishing the existing hospital. The outer islands are served by health dispensaries. The dispensaries and hospitals are operated by the RMI Ministry of Health. The hospital does not have neonatal intensive care units.

There are no private health care providers in the RMI. Emergency medical evacuations from the outer islands are by small aircraft during the daylight hours (the airstrips do not have landing lights). Medical evacuation by ship can take as long as two days, depending upon distance and sea conditions. Patients in the outer islands who require specialized care not available at Majuro or Ebeye are referred to Honolulu or other locations where such care is available. Medicaid is not available for citizens of the RMI. Private health insurance is not provided.

Growth Rate. The RMI is anticipated to expect a population growth rate. Based on the total fertility rate (TFR), two children born to each woman is the population replacement rate, which suggests that the country will have a stable population. If the TFR is below two children for each woman, there is an expected population decline; a TFR with more than two children suggests a growth rate for the population. The RMI TFR in 2012 was 3.37 children for each

woman. Population increases suggest difficulties for families and countries to meet family needs and country needs where resources are stretched and can become limited (e.g. finances, agriculture, employment, schools).

While the TFR reported is 3.37 per 1000, other reports indicate that women have more children. The Asian Development Bank on contraceptive acceptance indicated 37% (1463 men and women surveyed) practiced family planning, where two to four children were ideal for a family. The number of children per family, however, was five to seven. Some of the reasons for large(r) family sizes and lack of contraception use were that condoms reduced sexual pleasure and widespread fear for contraception use (e.g. the contraception drugs can lead to cancer)..

Title V. The RMI does receive funding under the Title V Block Grant and does operate Children with Special Health Needs (CSHN) Program. Newborn metabolic screening has not yet been instituted. Much of the funding from the CSHN program goes to funds off-island medical referral services for children, for example surgery for a child with a cleft palate. Children are referred usually either to Tripler Army Medical Center in Hawaii or to the Philippines National Children's Hospital in Manila.

Medical Home. The concept of the medical home is somewhat different in the RMI since there are no private physicians. Children receive their preventive care through Public Health Clinics held at the hospitals. On the outer islands, a Health Assistant provides well-baby check-ups. Maintaining adequate levels of immunization among children continues to be a challenge.

Home Visiting Program. The RMI is not eligible for financial assistance to provide a home visiting program under the Affordable Care Act. Public health nurses do make some home visitations, but not part of an organized program.

WIC. The RMI is not eligible to participate in the Women Infant and Children Nutrition Program.

Mortality and Morbidity. In 2010, the infant mortality rate was 22 (per 1000 live births), with the under age five mortality rate at 26 (per 1000 live births). The prevalence of tuberculosis (TB) was 231 per 100,000 population, with RMI having the world's highest rate of drug-resistant tuberculosis. The case detection rate for all forms of TB was 100. In 2009, 95% of all expenditures on health came from the RMI government. The per capita total expenditures on health averaged [redacted] per person. The probability of dying between 15 and 60 years per 1000 population was 407 (adult mortality rate). In 2009, there were only 44 people diagnosed with leprosy. A year later, however, in 2010, the number increased by 150% to 110 cases.

Cancer. The National Cancer Institute conducted research on cancer cases from the US nuclear weapon testing period in the 1940s and 1950s. They estimated 170 excess cancer cases with all but 65 to have likely have occurred as a result of the nuclear testing.. The types of cancers that were most common are radiation related were thyroid, and colon cancers.

Suicide. Suicide is a major health issue in the RMI and, was actually the fifth leading cause of death in 2004, primarily among males. The Ministry of Health links consumption of alcohol to suicides. While Marshallese women have a clearly defined role of caretaking and childbearing, men have a less defined role defined in a cash economy. Limitations in opportunities for employment, men face challenges in defined life roles. Some of the typical activities that men do include canoe building, fishing, and coconut tree climbing. While the fishing industry can provide an annual income of [redacted] on Kwajelein, these opportunities are limited, so the average household income on the outer islands is [redacted].

Services for Children with Hearing Loss

Description of the EHDI Program. The RMI EHDI (Early Hearing Detection and Identification) program is the nation's youngest. Established in the Maternal and Child Health Program, screening began in 2010. Audiological evaluations were last conducted three months later. All children identified at that time began receiving early intervention services. It was determined that legislation was not needed – the Ministry of Health authorized the screening to become the standard of practice. Data are entered into the HI*TRACK electronic data tracking system. A thorough description of the program status is contained in the Progress Report in Appendix 6.

Medical Services for Children with Hearing Loss. The RMI does not have an ENT specialist, but depends on irregular humanitarian visits from other countries. These ENT visits generally consist of clinical consultations, but not surgery. Neither is there a resident audiologist. Pediatric audiological services are provided on a contracted basis under funding from the HRSA grant. A hospital room was renovated to provide a sound-treated auditory test facility. Diagnostic equipment was budgeted under the HRSA grant but never purchased. There are no speech-language pathologists in the RMI. School services are provided for children ages 5-20 in special education classrooms. No forms of hearing amplification have been provided for the children.

Educational Services. The Ministry of Education is the largest agency of the RMI government. It oversees 75 public elementary schools enrolling about 8,000 students and 6 public secondary schools enrolling about 2,000 students. Additionally, 27 private elementary schools enroll 2,200 students, and 14 private secondary schools enroll about 1,000 students. Under the Compact of Free Association, funding for Head Start and Part C of IDEA was combined into one block grant. In the place of Head Start and Part C, the RMI established a nationwide kindergarten program. The RMI does receive funding under Part B of the Individuals with Disabilities Educa-

tion Act (IDEA). In 2009, 704 IDEA-eligible students were reported to the U.S. Department of Education, Office of Special Education Programs.

Information concerning the incidence or prevalence of hearing loss is difficult to obtain. The Gallaudet Research Institute, in its Annual State Survey, has not provided numbers and percentages of deaf and hard-of-hearing children in RMI. A literature search produced no publications on the prevalence of deaf and hard of hearing in RMI. The RMI does not have a school that serves the deaf and hard of hearing. Some families have relocated deaf children to Honolulu where they attend the Hawaii School for the Deaf and Blind.

Post-secondary training occurs mainly through the College of the Marshall Islands. The student body is homogenous, with almost all students of Marshallese ancestry. In February 2009, the College of the Marshall Islands, enrolling 740 students, was granted full academic accreditation by the US Western Association of Schools and Colleges. The Department of Education grants two-year degrees for general education teachers.

In the summer of 2010, a young deaf Marshallese woman who was completing a bachelor's degree at Gallaudet University came to Majuro, along with another Gallaudet Intern, to provide a summer program of services for school-aged deaf students. Copies of the articles on their activities is included in Attachment 1.

Parent Support/ Advocacy Groups. RMI does not have a parent group specific children with hearing problems. A chapter of *Family Voices* has not been organized in RMI. In 2011, a grant was written for a Community Parent Resource Center; however, that grant was not funded. Plans are to resubmit that grant this year. The parent (grandparent of a deaf daughter) is currently attending a six-month training program on disability advocacy at the University of the South Pacific in Fiji.

RESPONSE

The preceding Needs Assessment was intentionally long to give readers a picture of the RMI—an area vastly different in location, geography, and resources from any state. As graphically detailed in that section, the needs are great, and the challenges enormous, but the opportunity exists through HRSA funding to establish a system of care for persons with a hearing loss.

The Minister of Health is an elected Senator and a member of the President's Cabinet. That office requested the Center on Disability Studies at the University of Hawai'i (CDS-UH) to serve as a "Bona Fide" agent of the Ministry of Health to apply for this grant in recognition of its potential for substantial contributions to improving services not only for children with hearing loss but also for improving the capacity of the RMI to enhance surveillance for all children.

One of the priorities of the Ministry of Health has been development of an effective health information system. The Health Management Information System (HMIS), which is still being developed, is a computerized database using File Maker Pro software, to handle all health and health-related data. Similar to the bureaucratic hurdles encountered by the Newborn Hearing Screening Program, that project has encountered numerous problems in its development, including the reassignment of personnel. In 2011, the Ministry of Health asked the CDS-UH to serve as a "Bona Fide" on behalf to RMI to request funding from the Centers on Disease Control for an EHDI tracking system. That grant was funded for five years and work will commence for a data tracking system, *Identify and Follow: Ajiri in Ibwinini,* once newborn hearing screening again becomes operational.

Methodology: Goals and Objectives to Meet Program Requirements and Expectations

Goal 1: Improve, enhance, and expand the newborn hearing screening program to meet the 1-3-6 objectives.

1.1 Continuous quality improvement of newborn hearing screening to reduce refer rate.

1.1.1 Restart newborn hearing screening (prior to its suspension in February 2012, more than 99% of all infants were receiving an inpatient hospital screening)..

1.1.2 Provide additional training for screeners to reduce initial OAE refer rate to no more than 8%.

1.1.3 Reestablish a twice-a-week rescreening site at the hospital's auditory test room.

1.1.4 Provide support for transportation to the rescreening site for families when necessary.

1.1.5 Consider implementing AABR second-stage screening with a refer rate of no higher than 2%.

1.1.6 Make home visits to conduct rescreening for those babies who repeatedly fail appointments for rescreening.

1.2 Ensure timely audiological evaluations so that babies with hearing loss are diagnosed by three months of age. (currently there are 123 babies awaiting an audiological evaluation)

1.2.1 Schedule quarterly visits by pediatric audiologists.

1.2.2 Arrange ENT visits to occur concurrently with audiological visits

1.2.3 Maintain appropriate equipment for pediatric audiological evaluations

1,2,3 Develop mechanisms for dispensing hearing aids for babies needing amplification

1.3 Enhance system to provide high quality early intervention services to all babies identified with a hearing loss by six months of age.

1.3.1 Provide training to enhance capacity of community personnel to provide high quality early intervention services for children and their families..

1.3.2 Expand support resources for parents of children with a significant hearing loss.

1.3.3 Recruit local personnel to participate in the deaf education teacher training program begun at the CDS-UH.

Goal 2: Expand newborn hearing screening to the Ebeye hospital.

2.1 Meet with hospital and community personnel to obtain their support for the implementation of newborn hearing screening.

2.1.1 Provide a Grand Rounds presentation to staff on newborn hearing screening.

2.1.2 Identify nurses willing to conduct the screening activities.

2.1.3 Identify space in the hospital to modify for audiological testing.

2.1.4 Meet with special education and other community resources to identify opportunities for early intervention services.

2.2 Implement the screening program.

2.2.1 Obtain appropriate screening equipment.

2.2.2 Train nursing personnel to conduct the screening.

2.2.3 Implement the newborn hearing screening program on Ebeye

2.2.4 Expand the *HI*TRACK* data system to include data entry for Ebeye.

2.3 Expand diagnostic services to Ebeye

2.3.1 Modify the identified space for audiological testing..

2.3.2 Obtain appropriate audiological equipment

2.3.3 Schedule at least semi-annual audiological and ENT visits to Ebeye

Goal 3: Utilize other resources to build a sustainable system for children with hearing loss and other special needs.

3.1 Work closely with the Maternal and Child Health Program

3.1.1 Explore opportunities for development of newborn metabolic screening.

3.1.2 Explore possibilities of utilizing data tracking system to track immunization.

3.1.3 .Explore possibilities of developing an electronic birth certificate.

3.2 Explore options for expanding hearing screening into community private preschools

3.3 Explore options for expanding hearing screening to children living on the outer atolls.

3.4 Work closely with the Special Education program to develop services and resources for school-aged children with hearing loss.

Goal 4. Further enhance community support for the EHDI program

4.1 Establish a community advisory group

4.2 Establish a website for the program

4.3 Develop written materials for parents

4.4 Participate in a learning collaborative.

IMPACT

The project aims to make an systemic impact by improving the hearing health system of care available for children and adults in the RMI by expanding the resources available for children and adults with a hearing loss and ear disease. Previous to this project there were no resources for audiological assessment or rehabilitation. This project has already created a very adequate sound-treated room that can be used for assessments of infants, children, and adult. During the next three-year period, the audiological suite will be equipped for use by children and adults. As a hearing aid distribution system becomes a reality, this resource will not only provide amplification for infants, but for children and adults who have not previously had access to amplification. Similarly, when an otolaryngologist is brought to the RMI, after providing diagnostic and treatment services for infants, children and adults can receive services.

Pediatric Audiology. In most states and territories, a universal newborn hearing screening and intervention program has been built on an existing base of extensive services to children and adults with hearing loss. That was not the case in the RMI. At the beginning of this project,

the strategy that will be used to provide pediatric audiology through the use of consultants who are contracted for generally a week of services. National and international dissemination efforts are utilized to try to reach audiologists who might be willing to relocate to the RMI. Outreach will also be made to student in the MCH-Lend Audiology Trainee program to encourage them to consider providing services to this population.

As regular audiological services are established, attention will be given to developing a hearing aid dispensing system. Collaboration is occurring with Solar Ear to make low-cost hearing aids and solar-powered batteries available to children and adults in the RMI.

Newborn Metabolic Screening. Also, in every other state and territory, universal newborn metabolic screening existed before implementation of newborn hearing screening programs. No screening is done in the RMI for newborn metabolic disorders. A critically important impact will be if the resources and leadership of this effort can assist in the implementation of newborn metabolic screening in the RMI.

Plans for Dissemination of Results

The results of this program have been widely disseminated through regional, national, and international meetings. Presentations have been made at three Pacific Rim International Conferences on Disabilities. In the past, presentations were made at the Conference of the Association of University Centers on Disabilities in Washington, DC, at the American Public Health Association Meeting in Denver, and at the Division of Early Childhood of the Council on Exceptional Children in Kansas City. In this past year, a presentation was made at the International Society for Early Intervention Conference in New York City, and at the Association of University Centers on Disabilities in Washington, DC, and at the Association of Maternal and Child Health Programs in Washington, DC in February 2012.

A major purpose in these dissemination is to serve as a recruiting mechanism to either encourage specialized personnel (audiologists, teachers of the deaf, speech-language pathologists) to consider relocating to the RMI for a portion of their professional career or to volunteer to provide some itinerant humanitarian services.

The work being done in the Pacific Islands was highlighted during Mekong Sante in Phnom Penh, Cambodia, in January 2011. This presentation created interest in beginning newborn hearing screening in Cambodia. A similar presentation was made in Manila in 2011 to the Department of Pediatrics at the Philippine Children's Hospital. Options were explored for the potential recruitment of audiologists from the training program in Manila to consider opportunities for working in the RMI or other Pacific Islands.

No manuscripts have yet been submitted to peer-reviewed journals for publication. This will be a priority for this proposed grant period. An invitation has been received to prepare an article for a column entitled "Audiology without Borders" in the *Hearing Journal*.

A critically important aspect of dissemination has been accomplished through the local media. A number of newspaper articles and television interviews were done in the RMI during the first year of the project. Copies of those are contained in the Attachment 1.

Replicability and Sustainability

The challenges facing establishment of a universal newborn hearing screening program in RMI are very much like those that many of the nations in Oceania would face. Neither newborn hearing screening nor newborn metabolic screening is being done there. Addressing the challenges and establishing a viable, sustainable program in RMI could provide a model for replication elsewhere in Oceania or other developing countries.

Due to the state of the economy and the current level of governmental expenditures on health, sustainability of the program is unlikely without continued funding from the federal government. Efforts will be made to develop infrastructure capacity to mitigate any future reductions in federal funds and to seek alternative resources to meet specific needs that may develop.

EVALUATION PLAN

Evaluation of this project will focus on ensuring that a viable, high-quality program is implemented which will hopefully be sustained should federal resources cease. The vision driving development of this grant application is that all children with a significant hearing loss, through early identification and implementation of appropriate services, will be able to develop age-appropriate communication skills and participate successfully in the general curriculum to achieve improved educational and vocational outcomes. To accomplish this vision, parents need to be assisted in supporting the development of their children.

The project evaluation will be integrated into the project implementation. Integration will include both process and outcomes evaluation with objective performance measures based on data. The procedures will provide ongoing external and internal evaluation through provision of continuous feedback on the development of the project, the implementation of project activities, and the degree to which the project's objectives are met. The evaluation will also assess overall project impact.

Plan for Monitoring Process Indicators

The Ministry of Health has entrusted the management of this grant to the CDS-UH to improve the management efficiency enabling the program to achieve its goal and objectives more successfully. It will be necessary to monitor annually the increased efficiency of processing con-

tracts and payments and recruiting personnel. Improved capacity for meeting federal reporting requirements was another value in making the management change.

These process indicators will be monitored annually, and a written report will be sent to the Minister of Health in American Sāmoa.

Plan for Monitoring Health Performance Indicators

The "Identify and Follow: *Ajiri in Ibwinini"* logic model, as diagramed in Figure 2, will drive the evaluation process. For purposes of the CDC EDHI Surveillance System, Identify and Follow: *Ajiri in Ibwinini* reports will be used to monitor the following indicators on a monthly.

- What percentage of babies received an in-hospital screening? If this number falls below 95%, discussion will be needed with the EHDI Coordinator to determine why this is occurring.
- What was the hearing screening refer rate? The goal is for this number to be less than 5%. When the refer rate begins to exceed this number, discussions will be held with the EHDI Coordinator to look at the rate across screeners and determine if additional training may be needed.
- What was the rescreen refer rate? The goal is to have this number no more than 2%. Similarly, if the rate begins to exceed this percentage, discussion will need to occur to determine if the rescreening environment needs to be modified or if other changes should be made to keep the second rescreen rate as low as possible.
- Of those babies referred on the initial screening, what percentage were lost to follow-up and failed to receive the rescreening? The goal is to have this number as close to zero percentage as possible.

- How many out-of-hospital births occurred and what percentage of those babies received hearing screening by one month of age?
- How many babies received an audiological diagnostic evaluation by three months of age? This indicator has been one of the most problematic ones for the program over the past year. Currently, it has been more than 18 months since audiological evaluations have been provided in the RMI due to delays in executing contracts. This application is being submitted to resolve this problem. The goal will be to get this number as close to 100% as possible.
- How many babies were lost to follow-up prior to receiving an audiological evaluation? The goal will be for this number to be as close to zero as possible. The program will monitor those babies who are "found" after three months of age and eventually do receive an audiological evaluation after three months.
- How many babies with a hearing loss were enrolled in early intervention by six months of age? The goal for this measure is 100%. For those babies identified during the August 2010 audiological diagnostic evaluations, the number was 100%!
- How many babies, identified by the newborn hearing screening program, are receiving early intervention services?
- How many children were provided a means of amplification?
- What were the outcomes of those intervention services as measured by the communication skills of the child and the satisfaction of the families with services?

Monitoring of Newborn Metabolic Screening

The Maternal and Child Health Program in the Ministry of Health has as a priority, the implementation of newborn metabolic screening as soon as possible. As plans progress for the

implementation of newborn metabolic screening, efforts will be made to encourage the participation of pediatricians and newborn nursery staff in the annual EHDI meetings to enhance understanding of the importance of this screening and surveillance system. With the technical assistance that has been offered by NNSGRC, and the support of the Maternal and Child Health Program, newborn metabolic screening may well become a reality if the resources in this grant application become available.

As set forth in the objectives in this application, "Identify and Follow: *Ajiri in Ebwinini"* will be expanded to measure the following indicators.

- How many infants received blood-spot screening?
- What were the results of those screenings?
- How soon after the results were reported, were positive infants followed up?
- What were the results of the follow-up?

Monitoring of Other Health System Improvements

The project proposes even more ambitious efforts to further link health data for young children. These efforts propose that the following could be accomplished through this grant.

- An electronic birth certificate would be created.
- Hearing screening would be expanded to children in preschools with those records included in "Identify and Follow: *Ajiri in Ibwinini."* This expansion would create another opportunity to find those babies who had been lost to follow-up as well as to identify late onset and progressive hearing loss.
- "Identify and Follow: *Ajiri in Ibwinini"* would be further expanded to include immunization data, providing yet another opportunity to reduce loss-to-follow-up.

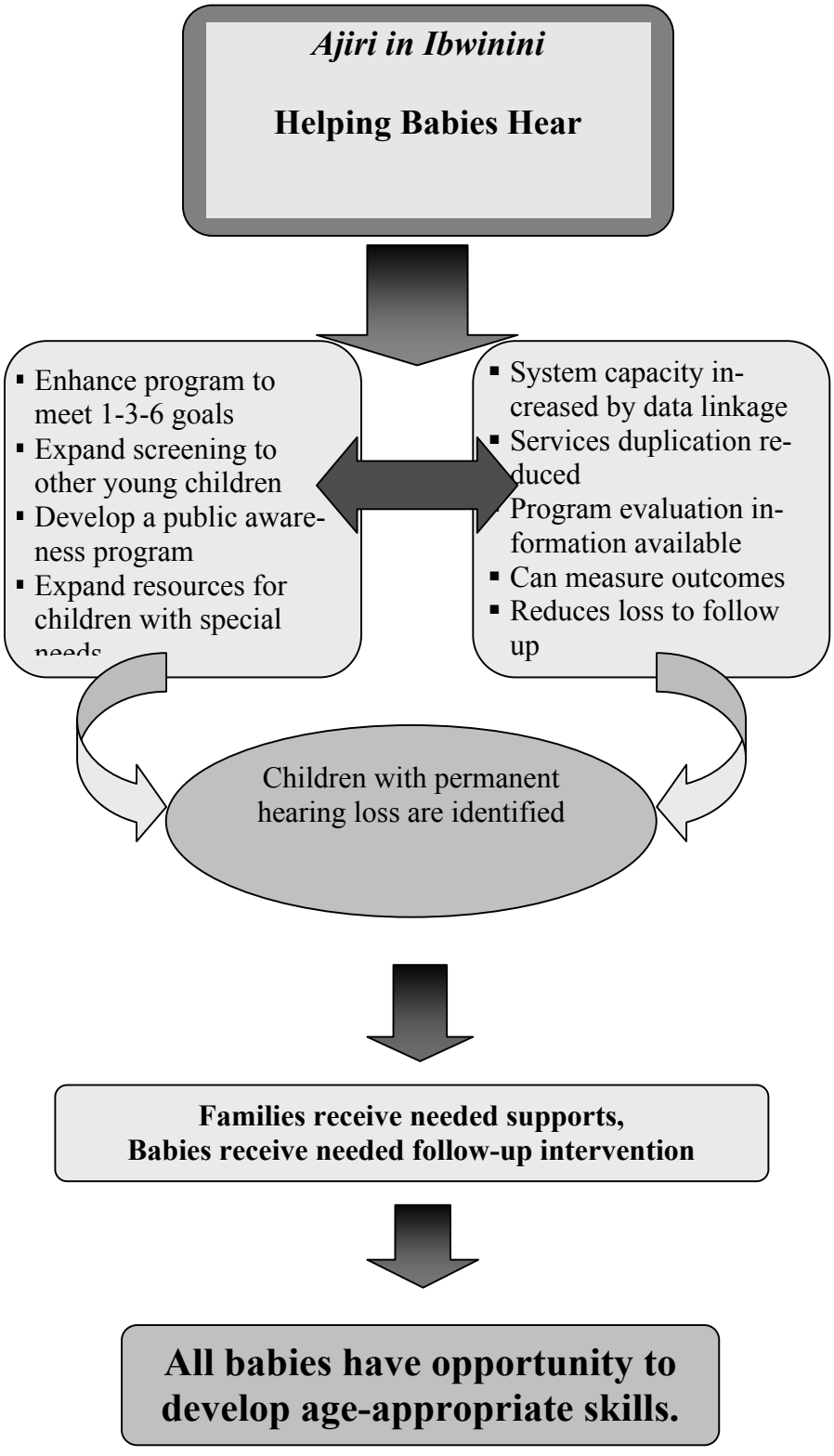
Process and Output Measures to Assess Timeliness, Completeness and Impact

The workplan, Table 2 at the end of the Project Narrative, outlines a description of the activities that will be undertaken to accomplish each of the objectives. Shown in the table is the responsible individual, the timeline for accomplishing the activities, and the performance indicator for evaluating how well the activity is accomplishing its objective.

Quality Assurance and Improvement Plan

The evaluation will be conducted by the Principal Investigator at the Center on Disability Studies at the University of Hawai‘i. The evaluator will not only assess status, will work with the project to overcome encountered barriers, and identify resources to assist the project in meeting any challenges it is encountering. The evaluation will be discussed during regularly scheduled calls with the Screening Supervisor and EHDI Coordinator.

Figure 3: Logic Model



RESOURCES/CAPABILITIES

Capacity and Infrastructure

Infrastructure capacity has been the greatest challenge in implementing newborn hearing screening. During the first year of the current three-year project, it took six months to get the technical assistance contract fully executed. But once that contract was executed, things moved rapidly and successfully. Providing training for screeners did not occur until May of 2010, nine months into the contract year. Over the next three months, the screening was conducted and a visit by a pediatric audiologist was scheduled for August 2010. The evaluation of that first year's accomplishments is fully described in Attachment 7. In summary, the program met its 1-3-6 goals, including getting a young child into early intervention services within one month of birth and one week of diagnosis.

Since that time, the program has been unable to achieve its goals. During the second project year, no technical assistance contract was ever executed. Although screening continued, no equipment or supplies were purchased and there was no audiological visit. Due to the difficulties being encountered during that year, and with the opportunity to apply for a data tracking grant from the Centers on Disease Control, the Ministry of Health asked the Center on Disability Studies at the University of Hawaii (CDS-UH) to apply for the grant on their behalf, as a "de facto agent."

Thus far, seven months into the third year of the grant, no contract has yet been executed and the program was unable to process purchase orders for supplies. Screening activities ceased in mid-February 2012 due to the lack of supplies. The program status was outlined in a memorandum from the evaluator to the Secretary of Health in October 2011. That memorandum is contained in Attachment 7, the Summary Progress Report. Based on the continuing bureaucratic

challenges the program encountered, the Secretary of Health requested the CDS-UH to apply on behalf of the RMI in the current competition to administer the grant on behalf of the RMI. That request letter is Attachment 4 of this application.

Description of Organization

The Center on Disabilities Studies at the University of Hawaii (CDS-UH) will manage this project on behalf of the RMI. One of 57 national University Centers of Excellence in Developmental Disabilities, the CDS-UH is the only organizational unit with a focus on training, research and service for persons with disabilities within the 10 campuses of the University of Hawaii System. Located at the University of Hawaii at Manoa, a Tier 1 Research Institution, serving more than 20,000 students, the CDS-UH has access to the full resources of the UH System. Established in 1987, the UH Board of Regents officially designated the CDS-UH as a Research Center in 2000. Currently, there are about 100 faculty and staff that manage over 50 different federal and state grants, with an annual budget of more than twenty million dollars.

Since its beginning the CDS-UH has had a commitment to employment of persons with disabilities and to parents or family members of a child with a disability. Currently, approximately 37% of the staff and faculty self-identify as a person with a disability and another 32% identify themselves as a parent of family member of a person with a significant disability. The CDS-UH ethnicity profile demonstrates its success in recruiting persons from culturally and linguistically diverse backgrounds, with faculty and staff fluent in 17 difference languages.

Staffing and Management Plan

Resumes for the key personnel who will be involved in the project are Attachment 3 and position descriptions are included in Attachment 2. An organizational chart for the program is

included as Attachment 5. All the following personnel have extensive experience in the implementation of newborn hearing screening and tracking activities.

Principal Investigator. Dr. Jean Johnson will serve as the Principal Investigator of the project, overseeing the administration activities and the implementation of the project for the RMI. She wrote the initial three year grant and has provided technical assistance and served as the evaluator in the first three-year application. She serves in a similar capacity as the Principal Investigator for the American Sāmoa Helping Babies Hear HRSA grant and the CDC SILAS II grants.

EHDI Coordinator. A full-time EHDI coordinator will be recruited, with funding split between the HRSA and CDC grants. This individual will serve as the coordinator for loss-to-follow-up. Efforts will be made to recruit an individual who has experience with young children to be able to provide early intervention ser vices. For the past three years, the EHDI Coordinator has also been the Maternal and Child Health Coordinator and responsible for a range of programs. Under a new reorganization in the Ministry of Health, this individual, Ms. Hellen Jetnil-David has been assigned additional responsibilities for all public health programs except for communicable disease. These new responsibilities will consume so much of her time that it is now necessary to recruit someone with primary responsibilities for the EHDI program.

Management Plan

The organizational chart for the project is in the Appendix. Although the management structure has changed from the first three-year *Ajiri in Ibwinini* grant, the personnel will remain changed, but with the addition of a new position for the EHDI Coordinator. The personnel are well known to each other, have good working relationships, and are committed to making the

program a success. The CDS will administer the project in collaboration with the Maternal and Child Health Program.

Ms. Agnes Flood will continue to serve as the Screening Supervisor. She has done an outstanding job these past three years in maintaining screening activities under adverse circumstances. She has also been responsible for entering data into the HI*TRACK system.

Communication will largely be by email. However, the Principal Investigator in Hawai‘i and the staff in the RMI have Skype capacity to enable “person-to-person” communication for regular management meetings and whenever a special need arises. The Principal Investigator will make two-on-site visits during each year of the grant.

Work Plan

The work plan for the project and the evaluation indicators are outlined in Table 2 on the following pages.

Table 2. *Ajiri in Ibwinini* Work Plan and Evaluation Indicators September 1, 2012 – August 30 2015

Goal 1: ***Improve, enhance, and expand the newborn hearing screening program to meet the 1-3-6 objectives.***				
Objectives	**Activities**	**Responsible Persons**	**Timeline**	**Evaluation Indicators**
1.1 Continuous quality improvement of newborn hearing screening to reduce refer rate	Restart newborn hearing screening to screen at least 99% of all newborns	EC, SS	Oct. 2012	Data reports
	Provide additional training for screeners to reduce initial OAE refer rate to no more than 8%	PI, EC, PA	Oct. 2012	Data reports
	Reestablish twice-a-week rescreening site in the hospital's auditory test room	EC, SS	Oct. 2012	Data Reports
	Provide transportation support for families to the site when necessary	EC, SS	Continuously	Record of support
	Implement AABR second-stage screening with a refer rate of no higher than 2%	PI, EC, PA	Sept. 2013	Data reports
	Make home visits to conduct rescreening for those babies who repeatedly fail appointments for rescreening	EC, SS, S	Oct. 2012	Data Reports
1.2 Ensure timely audiological evaluations so that babies with hearing loss are diagnosed by three months of age	Schedule quarterly visits by pediatric audiologists	PI, EC, PA	Quarterly	Data reports
	Arrange ENT visits to occur concurrent with audiological visits	PI, EC, OT	July 2012	Data reports
	Maintain appropriate equipment for pediatric audiological evaluations	PI, EC, PA	Quarterly	Data reports
	Develop mechanisms for hearing aid dispensing for babies needing amplification	PI, PA, EC	June 2013	Data reports
1.3 Enhance system to provide high quality early intervention services to all babies identified with a hearing loss by six months	Provide training to enhance capacity of community personnel to provide high quality early intervention services for children and their families	PI, EC, PE	Nov. 2012	Training reports
	Expand support resources for parents of children with a significant hearing loss	EC, PC	April 2013	Reports of training events (Hands and Voices)

of age	Recruit local personnel to participate in the deaf education teacher training program begun at the CDS-UH	PI, EC, PE	Aug. 2013	Student enrollment

Goal 2. ***Expand newborn hearing screening to the Ebeye Hospital***

Objectives	Activities	Responsible Persons	Timeline	Evaluation Indicators
2.1 Meet with hospital and community personnel to obtain their support for the implementation of newborn hearing screening	Provide a Gant Rounds presentation to staff on newborn hearing screening	PI,PA, OT, EC	Oct. 2014	Training agenda and evaluation
	Identify nurses willing to conduct the screening activities	EC, SS	Oct. 2014	Data Reports
	Identify space in the hospital to modify for audiological testing	PI, PA	Oct. 2013	Diagrams
	Meet with special education and other community resources to identify opportunities for early intervention services	PI, EC,PE	Oct. 2013	Meeting agendas
2.2 Implement the newborn hearing screening program	Obtain appropriate screening equipment	PA, EC	Nov. 2013	Purchase orders
	Train nursing personnel to conduct the screening	PA, SS	Dec. 2013	Training evaluations
	Implement universal screening	SS, SC	Jan. 2014	Data reports
	Expand the HI*TRACT data system to include data entry for Ebeye	EC, SS	Dec. 2013	Data reports
2.3 Expand diagnostic services to Ebeye	Modify the identified space to create a sound-treated space for audiological testing	PI, EC	Jan. 2014	Diagrams, Pictures

	Obtain appropriate audiological equipment	PI, EC, PA	March 2014	Purchase orders
	Schedule quarterly audiological and ENT visits	PI, EC, PA, OT	May 2014	Data reports

Goal 3: ***Utilize other resources to build a sustainable system for children with hearing loss and other special needs***				
Objective	**Activities**	**Responsible Persons**	**Timeline**	**Evaluation Indicators**
3.1 Work closely with the Maternal and Child Health Program	Explore opportunities for implementation of newborn metabolic screening	PI, MC	Jan. 2014	Documentation
	Explore opportunities for linkage with immunization data tracking to improve immunization rates	PI, MC	July 2014	Documentation
	Explore opportunities for developing an electronic birth certificate	PI, MC	Jan. 2015	Documentation
3.2 Explore possibilities for expanding hearing screening into community private preschools	Meet with community private preschools to gauge their interest	EC	July 2014	Documentation
	Obtain funds for equipment and supplies	PI, EC, MC	Oct. 2014	Documentation
	Train personnel or fund existing screeners	EC, MC	Jan. 2015	Data Reports
3.3 Explore options for expanding hearing screening to children living on the outer atolls	Assess resources for expanding screening, diagnostic services and intervention services	PI, EC, MC	Jan. 2015	Documentation
3.4 Work closely with the Special Education Program to develop services and resources for school-aged children	Extend diagnostic and rehabilitation resources to the Department of Education	PI, EC	April 2015	Documentation

with hearing loss				

Goal 4: ***Further enhance community support for the EHDI Program***				
Objective	**Activities**	**Responsible Party**	**Timeline**	**Evaluation Indicators**
4.1 Establish a community advisory group	4.1.1 Work with Maternal and Child Health Program to establish a community advisory group	PI, EC, MC	July 2013	Documentation
4.2 Establish a website for the program	4.2.1 Contract with NCHAM to establish a website for the program	PI, EC	Jan. 2013	Documentation
4.3 Develop written materials for families	4.3.1 Review national and regional resources and develop culturally competent written materials for Marshallese families	EC, MC	June 2013	Evaluation of the materials
4.4 Participate in a Learning Collaborative	4,4.1 At the invitation of HRSA, participate in a learning collaborative	PI, EC	TBD	Documentation

Responsible Parties:

PI: Principal Investigator
EC: EDHI Coordinator
SS: Screening Supervisor
SC: Screeners
PC: Parent Consultant
MC: Maternal-Child Health Coordinator

Technical/Consultant Support

PA: Pediatric Audiologist
OT: ENT Specialist
PE: Parent Educator
NN: National Newborn Screening & Genetic Resource Ctr
NA: National Association Public Health Statistics & Information Systems