

PROJECT NARRATIVE – YEAR I*Ajiri in Ibwinini***Budget Period 9-1-12 through 8-31-13****1. Project Identifier Information**

HRSA Grant No: H61MC24884-01-01

Project Title: *Ajiri in Ibwinini*

Organization Name: Center on Disability Studies, University of Hawaii
(as de facto agent for the Republic of the Marshall Islands)

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2. Accomplishments

This has undoubtedly been the most successful year of the project. Equipment and supplies have been obtained, personnel have been recruited, diagnostic audiological visits have occurred as planned, and early intervention services are being initiated. The initial major accomplishment was the transition of program management from Ministry of Health (MOH) to the University of Hawaii's Center for Disability Studies (UH-CDS). This new management approach was necessary to carry forward program activities without being constantly interrupted due to lingering red-tape and bureaucratic mishaps.

In November of 2012, the program resumed screenings both inpatient (initial) and outpatient (follow-up) after about a seven month cessation. Thus the goal to screen at least 99% of all newborns has not been met. The initial screening rate for all newborns this year is 87%.

This is largely due to the fact that both OAE screening equipment/machines malfunctioned in August and were sent overseas for calibration. In November, as mentioned earlier, screenings resumed. Since then, the screening rate has kept steady between 99-100%.

During Dr. Weirather's third Audiological visit in March of this year, she provided a brief AABR Accuscreen two-stage screening training for the screeners. This has tremendously reduced inpatient refer rate from 20.5 % in March to just 8.1% in May. Thus it is evident that this rate will continue to drop.

Recruitment of Personnel. The greatest achievement of the project this year was the successful recruitment of permanent program staff for the first time in the history of the program. Ms. Chinilla Pedro began as the RMI EHDI Coordinator in January 2013. This is the first time that the program has had a full-time, dedicated coordinator. Her resume is included as Attachment 2. She was provided opportunities for professional development in Hawaii to visit that state's EHDI program and to learn about other providers in the state who were serving children with a significant hearing loss.

In addition to Ms. Pedro, Ms. Agnes Flood was recruited (on a part-time basis) as the EHDI Screening Supervisor. She brings a wealth of experience to this position. She has also been given the opportunity to participate in a number of professional development opportunities. In addition to her work in providing back-up screening and rescreening services, she is also responsible for the data entry for the program. Along with Ms. Flood, two hospital registered nurses have been recruited to provide screening services on a part-time basis.

The program was further delighted to be able to recruit an EHDI Champion for the Marshall Islands, Dr. Nester-Agatha Devesi. He is proving to be an invaluable asset to the program. Fortunately, he was able to attend the annual EHDI Conference in Arizona in April.

Nancy Rushmer, Early Intervention Consultant. Ms. Nancy Rushmer spent two weeks in Majuro in May providing training, home visits to families, and one-on-one training for the EHDI Coordinator to provide initial early intervention services. A table was constructed of those children needing services, including those children in continuing need of cleft lip and palate repairs. During the month of June, an advertisement is appearing in the local newspaper in hopes of recruiting a qualified early intervention teacher, part-time.

Charles Scheier, Information Technology Consultant. In June, Mr. Scheier provided services to help identify the information technology services needed to meet the needs of the newborn hearing screening program and to provide accessible information on other children with special needs.

Barriers

The primary barrier experienced during the year was the delay in progress to expand newborn hearing screening to Ebeye Hospital. Plans were made to meet with Ebeye Administrator Tommy Milne in March. Unfortunately Mr. Milne became very ill and was referred to Saint Lukes Hospital in Manila, Philippines for further care and treatment. Having Mr. Milne in the discussions is very critical to this objective, so the meeting had to be postponed. The visit was rescheduled for May. However, this trip had to be cancelled on short notice as Principle Investigator seriously injured her knee and had to undergo intensive physical therapy. These two unfortunate events have led to a delay in achieving this objective. Current plans are to reschedule Ebeye visits sometime in July and August.

3. Goals and Objectives

The progress toward meeting the original goals and objectives is clearly delineated in the attached Work Plan-Evaluation table at the end of this Project Narrative. The program is pleased to note that it is on target to meet all goals as outlined in the original grant application.

4. Significant Changes

Children with Special Needs. A major issue has emerged which may result in significant changes over the coming year. In developing the program, it was acknowledged that there was no early intervention program present in Majuro. What was not fully understood was the dearth of any services for children with special needs under the age of five.

As a result of the diagnostic services provided to children referred from newborn hearing screening, a large population of children has emerged with special needs that are not being addressed. Eleven children under the age of seven have been identified with cleft lip and palates, generally unrepaired or in need of further services. No speech-language pathology services exist. Children have been identified with Down Syndrome, cerebral palsy, and developmental delay. Additionally, a number of young deaf children have been identified who are not reaching services under Part B of IDEA due to an apparent restriction on school entry for any child under the age of five.

The needs of these children cannot be ignored – and resources must be identified to meet the needs of these children!

Chronic Middle Ear Disease. The ENT consultant has documented the prevalence of chronic middle ear disease that complicates the timely diagnosis of a hearing loss. One solution appears to be training a local pediatrician in the insertion of PE tubes. This approach was

approved by the Chief Medical Officer. An ENT surgeon will be in Majuro in June to provide this training.

5. Plans for Coming Budget Year

Two plans are paramount for the coming budget year, in addition to maintaining the high-quality screening services and regular audiological diagnostic visits. The first is to ensure that the newborn hearing screening begins to take place at Ebeye Hospital. Currently, the Principal Investigator and EHDI Coordinator are scheduled to travel to Ebeye in July to begin planning and to arrange for the modification of the available physical facilities to create a sound-treated environment suitable for the testing of infants.

The second priority is to work to create regular, high-quality early intervention services for those children identified by the program. Because of limited space at the Majuro Hospital, one option that will be explored during the visit to Ebeye will be the donation of a trailer by the Kwajalein Base to create a center-based early intervention program.

EVALUATION OF YEAR I OF IMPLEMENTATION.

Table 1. *Ajiri in Ibwini* Work Plan and Evaluation Indicators September 1, 2012 – August 30, 2013

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 [Overall, 87% of the newborns were screened prior to discharge, with 1.3% deceased, and only 11.7% not screened prior to discharge. This percentage was low overall for the budget period, because the program had equipment and supply problems in the first three months. Since then, rates have improved dramatically with 99% of the babies being screened.]	EC, SS	Oct. 2012	Data reports
	Provide additional training for screeners to reduce initial OAE refer rate to no more than 8% [Accomplished. An AccuScreen was purchased and two-stage screening implemented, drastically reducing the refer rate.]	PI, EC, PA	Oct. 2012	Data reports
	Reestablish twice-a-week rescreening site in the hospital's auditory test room [Accomplished. The screening supervisor provides rescreening twice-a-week.]	EC, SS	Oct. 2012	Data Reports
	Provide transportation support for families to the site when necessary [Still developing mechanisms to provide this.]	EC, SS	Continuously	Record of support
	Implement AABR second-stage screening with a refer rate of no higher than 2% [Completed]	PI, EC, PA	Sept. 2013	Data reports
	Make home visits to conduct rescreening for	EC, SS, S	Oct. 2012	Data Reports

	those babies who repeatedly fail appointments for rescreening [Limited success with this thus far. The hospital-based screening appears to be working adequately.]			
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 [Quarterly visits have occurred this year.]	PI, EC, PA	Quarterly	Data reports
	Arrange ENT visits to occur concurrent with audiological visits [With other visiting ENT services this past year, ENT visits have been limited to only two.]	PI, EC, OT	July 2013	Data reports
	Maintain appropriate equipment for pediatric audiological evaluations [Unit is fully equipped with state of the art equipment except for diagnostic ABR equipment which is rented for each visit.]	PI, EC, PA	Quarterly	Data reports
	Develop mechanisms for hearing aid dispensing for babies needing amplification [In process. Plans had been made to dispense aids in the June 2013, visit; however, difficulty has been encountered in obtaining low-cost aids from a humanitarian organization.]	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 of age	Provide training to enhance capacity of community personnel to provide high quality early intervention services for children and their families [Accomplished. Nancy Rushmer was in Majuro for two weeks in May providing training and direct early intervention services.]	PI, EC, PE	June 2013	Training reports
	Expand support resources for parents of children with a significant hearing loss [In progress]	EC, PC	April 2015	Reports of training events (Hands and Voices)
	Recruit local personnel to participate in the deaf education teacher training program begun at the CDS-UH [In progress]	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 [Visit planned for July 2013]	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
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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 with hearing loss	Extend diagnostic and rehabilitation resources to the Department of Education	PI, EC	April 2015	Documentation

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 UH-CDS to establish a website for the program [In progress]	PI, EC	Jan. 2014	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 [In progress]	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 [Awaiting an invitation from HRSA]	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