

ABSTRACT

Project Title: *Ulua`i Laona – Helping Babies Hear*
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Problem. American Sāmoa initiated universal newborn hearing screening in January 2009. For the first three years the program was managed by the Department of Health in American Sāmoa. For the past three years and for the current application, they have requested that the Center on Disability Studies at the University of Hawai`i serve as their *de facto agent* for the application.

Goals and Objectives. The following are the goals and objectives for the three-year grant.

1. Maintain and improve the newborn hearing screening program to meet 1-3-6 goals.
 - 1.1 Maintain current screening, diagnostic and intervention services.
 - 1.2 Establish a Quality Improvement Team.
 - 1.3 Review all data to identify areas where improvement is needed.
2. Reduce loss to follow-up at all stages of the process to ensure all babies receive follow-up.
 - 2.1 Expand early childhood hearing screening to day care and preschools.
 - 2.2 Extend hearing screening to WIC program.
 - 2.3 Collaborate with new home visitation program to identify babies.
 - 2.4 Coordinate with Head Start hearing screening program.
3. Utilize other resources to build a sustainable system of care for children with special needs.
 - 3.1 Continue advocacy for newborn metabolic screening.
 - 3.2 Work to reduce the prevalence of chronic middle ear disease.
 - 3.3 See additional amplification options for children with permanent hearing loss.
 - 3.4 Expand support resources for parents.

Methodology. Dedicated local staff will implement the project with management support and technical assistance from the University of Hawai`i. This arrangement has worked successfully for the past four years. Expertise will be recruited and contracted to provide pediatric audiology and specialized early intervention services.

Coordination. The letters of support documents the coordination that has taken place over the past three years and that will continue. The project has the support of the Director of the Department of Health, the Chief Executive Officer of the LBJ Tropical Medical Center (the territory's only hospital), and the nursery and pediatric staff. Coordination will be expanded to include day care providers, preschools, Head Start, and the new home visitation program.

Evaluation. An evaluation plan is detailed based on a logic model. This plan goes beyond monitoring the 1-3-6 goals to include results of newborn metabolic screening, and early intervention indicators.

Annotation. This project will improve, enhance, and expand the universal newborn hearing screening program to meet the 1-3-6 goals and reduce loss to follow-up at each of the stages.

ULUA'I LAONA – (HELPING BABIES HEAR)

PROJECT NARRATIVE

INTRODUCTION

This application, entitled *Ulua 'i Laona* (Sāmoan for “helping babies hear”), is submitted on behalf of American Sāmoa to further improve, enhance, and expand its newborn hearing screening program. Five-and-one-half years ago, American Sāmoa became the last U.S. territory to begin universal newborn hearing screening. The first three-year grant experienced significant challenges in implementation. These challenges included the following: the world-wide recession; political turmoil in the Territory; a devastating tsunami; and extreme difficulty in recruiting personnel, obtaining equipment and supplies, and contracting for needed consultants. The second three-year grant, which was contracted through the University of Hawai‘i, has been a period of successful capacity building, with recruitment of competent, well-trained staff, obtaining state-of-the art equipment, and utilization of consistent diagnostic consultants.

A third three-year grant provides the opportunity for implementing a process of quality improvement identified by the National Initiative on Child Health Quality to create the best possible system of care for newborns identified with a hearing loss. The process, as appropriate for the territory, will be imbedded in the protocols to minimize any potential loss to follow-up. This application directly addresses the Healthy People 2020 ENT-VSL, 1.1, 1.2, 1.3, and 2 (Reduce Otitis Media). Because American Sāmoa is far from the mainland United States and so unusual in its geography and resource capacity, an extensive description of American Sāmoa is presented in the Needs Assessment Section to help grant-reviewers better understand the challenges that exist in implementing newborn hearing screening in such a remote and rural location far from professional resources.

NEEDS ASSESSMENT

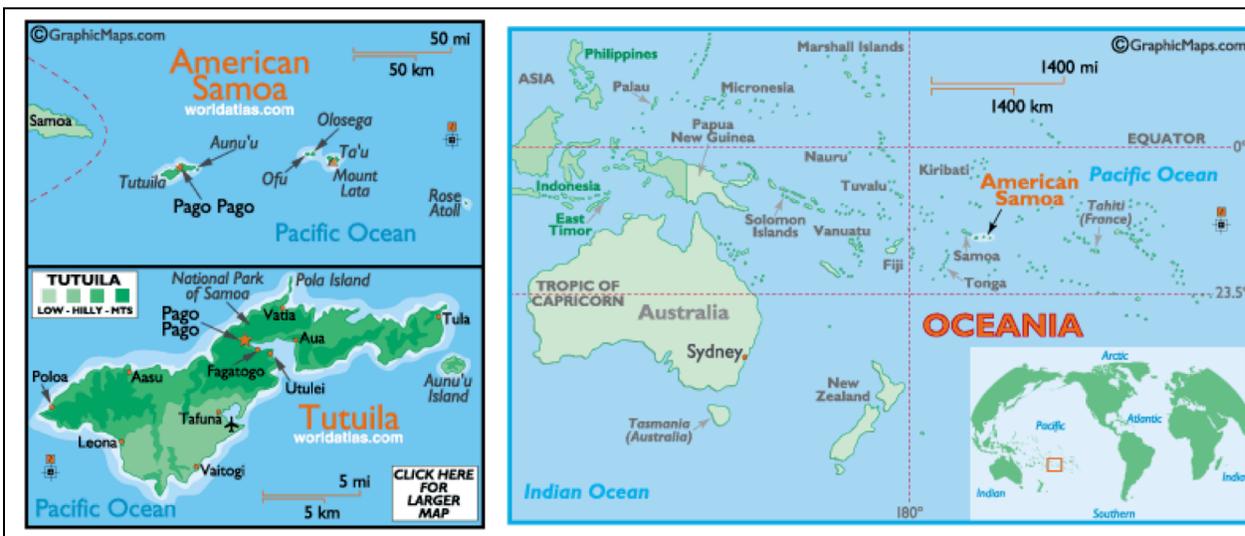
Location

American Sāmoa is an unincorporated territory of the United States, located in the South Pacific. It is the only part of the United States in the Southern Hemisphere. Located just east of

the International Dateline, it is 2,600 miles from Hawai‘i and 4,800 miles from the United States mainland. Its closest neighbor is the nation of Sāmoa, formerly called Western Sāmoa, about 60 miles away. The area has been under American control since the 1899 Treaty of Berlin, in which Germany and the United States divided the Sāmoan archipelago.

American Sāmoa consists of seven islands—five are volcanic islands and two are coral atolls. The land area of the territory is 76 square miles, just slightly larger than the District of Columbia. The largest and most populous island is Tutuila, where the deep-water port of Pago Pago and the international airport are located. The capitol and the legislature are also located on Tutuila. The other primary populated islands, Ta‘u and Ofu, are eight-hours away by boat or 20-minutes away by air with round-trip airfare of ██████. Between December and March, the area is frequently hit by typhoons. The temperature averages 82.1 degrees Fahrenheit, with annual rainfall of 160 inches. The location is shown on the maps below.

Figure 1. Map of American Sāmoa Islands and its Location in Oceania.



<http://www.worldatlas.com/webimage/countrys/oceania/as.htm>

Politics

Politics of American Sāmoa take place in a framework of a presidential representative democratic dependency. The Governor is the Head of Government, and the U.S. President is Head of State. The territory is administered by the Office of Insular Affairs of the U.S. Department of the Interior. The American Sāmoa Legislature consists of a 21-seat, popularly elected House of Representatives, and an 18-seat Senate whose members are elected by local chiefs. The judiciary is independent of the executive and the legislature. American Sāmoa elects one non-voting delegate to the U.S. House of Representatives. The Constitution was ratified in 1966.

Governance also includes the traditional village politics of the Sāmoan Islands, the “fa‘amatai” and the “fa‘aasamoa.” These continue in American Sāmoa and in independent Sāmoa, and interact across the current boundaries. The Fa‘asamoa comprises the language and customs, and the Fa‘amatai the protocols of the “Fono” (council) and the system of Matai (chiefs). The Fa‘amatai and Fono take place at all levels of the Sāmoan body politic, from the family, to the village, to the region, to the nation.

The Matai are elected by consensus within the Fono of the extended family and village or villages concerned. The Matai and the Fono (which is itself made of Matai) decide on distribution of family exchanges and tenancy of communal lands. The majority of lands in American Sāmoa are communal. A Matai can represent a small family group or a large extended family that reaches across islands.

Demographic Data

Persons born in American Sāmoa are American Nationals, but not United States citizens. The population in the territory shows a steady decline, from 68,200 in 2007 to 65,628 in 2009,

and is currently estimated at approximately 55,000. Out-migration due to high unemployment is a likely reason for the decrease. In 2010, the unemployment rate was 23.8%, or approximately three times the U.S. national rate. The population is predominately Pacific Islander. More than 93% of the population consists of Pacific Islanders, with Sāmoans being the vast majority (88.2%), followed by a small percentage of Tongans (2.8%). Immigration from Southeast Asian countries is increasing, with Filipinos currently composing just under 2% of the population. English and Sāmoan are official languages, with only about 40% of the population fluent in English. Sāmoan is the language of instruction in the public schools.

In 2011, the per capita income of American Sāmoa was ██████████, by far the lowest in the United States. Some 58% of all families (and 61% of all individual persons) live beneath the U.S. federal poverty level. Almost 40% of residents do not have adequate indoor plumbing. One in ten families is headed by a female householder with children.

The social services support system is quite different from that of the U.S. or other U.S. territories. Temporary Aid to Needy Families (TANF) is not available to people in American Sāmoa. Only persons with a disability are eligible for food stamps (otherwise, almost the entire population would qualify). The nutrition program, Women, Infants and Children, is a resource for pregnant and nursing women, infants, and young children.

Religion plays a prominent role in the lives of American Sāmoans. The motto of the territory is "*Sāmoa, Let God Be First.*" A drive around Tutuila suggests that probably the church-to-population ratio is among the world's highest. The predominate Christian religions are Congregational, Mormon, and Catholic, with all major protestant groups represented.

Due to limited economic opportunities, enlistment in the U.S. military is a popular choice for Sāmoan youth. The islands are described as having the highest percentage recruitment of any

area of the United States. The proportional percentage of deaths from the wars in Iraq and Afghanistan is higher than any state or territory. Several dozen young men and women from American Sāmoa have lost their lives over the past decade in those far-away conflicts.

Transportation

Air transportation is provided to and from the United States by a single carrier and consists of twice-weekly (Monday and Thursday) five-hour flights from Honolulu. Local airlines serve the other islands. An extensive system of privately owned busses serves the island of Tutuila, with fares varying from 50 cents to three dollars one-way. Privately owned taxis also serve the island.

Educational Services

The territory has 28 public schools—22 elementary, 5 secondary, and one vocational-technical school—all operated by the American Sāmoa Department of Education. Private schools, operated by religious institutions, number 15. About 19,000 students are enrolled in the public and private schools. The *Individuals with Disabilities Act* (IDEA) extends to American Sāmoa. However, specialists in related services are virtually non-existent.

Founded in 1970, American Sāmoa Community College, accredited by the Western Association of Schools and Colleges, provides post-secondary education on the islands. The enrollment in 2011 was 1,537. The University of Hawai‘i has faculty located in the territory to provide on-island coursework to cohorts of students working toward the bachelor’s degree in elementary education. Students in the cohort can also obtain a certificate in special education. A focus of those efforts has been on training paraprofessional Related Service Assistants (RSAs) to provide hands-on services in the absence of professional clinicians.

Health Services

American Sāmoa is served by one tertiary care hospital, the Lyndon B Johnson Tropical Medical Center (LBJ). The facility is almost half a century old and in need of major maintenance and capital improvements. The Maternal and Child Health Program estimates that only 20% of women in American Sāmoa receive adequate prenatal care, with about one-third of women receiving no prenatal care at all. The annual number of births has shown a steady decrease over the past eight years. As shown in Table 1 there were 20% fewer births in 2013 than 2006. The cause for this drop is uncertain. While it may partly be a change in birth rate per woman, another reason could be the much tighter control on immigration policies since 2001, resulting in fewer women from the nation of Sāmoa coming to American Sāmoa to deliver. In the past, many women from Sāmoa came to American Sāmoa to deliver their babies because of the higher quality of health care available. Also, birth in American Sāmoa conferred on the baby status as an American National.

Table 1. Birth Statistics

Year	Number of Births
2006	1,442
2007	1,362
2008	1,349
2009	1,367
2010	1,279
2011	1,287
2012	1,175
2013	1,164 (Est.)

Out-of-Hospital Births. Obtaining an exact annual number of out-of-hospital births is not possible. However, in response to the question about the number of out-of-hospital births, Vital Statistics, MCH, the CEO of the LBJ, and a staff pediatrician, all stated that the percentage was quite low.

Neonatal Intensive Care Services. The territory divides its newborn nursery into the regular nursery and a 4-5 bed maximum level II/level III (step-down) neonatal care unit. Several neonatal-appropriate ventilators are available. All major ventilator “modes” are available except Oscillation or High Frequency Ventilation. The neonatal care unit has adequate neonatal monitors. Attempts are made to resuscitate preemies down to a low of 750 grams birth weight. One modern incubator is available. The unit is managed entirely by general pediatricians.

Off-Island Care. In some cases, babies from American Sāmoa are taken to Honolulu for critical medical care. One tragic event occurred on February 8, 2008, when a two-week old baby from American Sāmoa (being sent to Hawai‘i for possible cardiac surgery) died while being detained in a locked room in the Honolulu Immigration Office. The baby and the accompanying nurse had paperwork specifying their status as American nationals, but the baby’s mother did not. The result was a fatal delay in admitting the three of them.

Third-Party Payers. Medicaid is not available as an entitlement in American Sāmoa. Instead, the Centers for Medicaid and Medicare make a lump sum payment each year to the LBJ to partially cover the cost of serving low-income patients. The current match for American Sāmoa is 50:50. Thus, the important resource of the Early, Periodic, Diagnostic, and Screening Program (EPSDT), with its requirement to provide treatment for identified problems, is not available to children in American Sāmoa.

The State Children’s Health Program (SCHIP) is also operated as a block grant, not based on individual eligibility. The prioritized use of the SCHIP funds are for school dental services, immunizations, children’s mental health services, and support for contracted pediatricians. The Title V, Children with Special Health Needs Program is not providing any funds for audiological

evaluations or for hearing aids for children with significant hearing loss. There are no private insurance plans in American Sāmoa.

Medical Providers. Traditionally, medical services have not been provided by medical doctors with the level of training required in the United States. Rather, primary providers have been Medical Officers who received six years of post-high school training in the Fiji School of Medicine.

Medical Home. The concept of “Medical Home” operates somewhat differently in American Sāmoa. Acknowledging that a medical home is not a building, house, or hospital, but rather an approach, the combined resources of the LBJ and Public Health provide comprehensive primary care to infants and children in the territory.

American Sāmoa has no chapter of the American Academy of Pediatrics. Most primary care is provided through five different public health clinics. Well-child care is provided through this network of clinics. If tertiary care is needed, families are referred to the LBJ, where a co-payment of ■■■ is required for services and another ■■■ co-payment for any medications. Among this program’s greatest assets in the community are the three U.S. trained and board certified pediatricians and one board certified pediatric nurse practitioner, a team headed by the EHDI super champion, Dr. James Marrone.

Diseases. Heart disease remains the leading cause of death, followed by malignant neoplasm and diabetes mellitus. The rate of diabetes is epidemic: 49% of the population has diabetes, the highest rate in the Pacific. Among adults ages 25-64, 93.5% are overweight or obese, with little difference between age groups. Dengue fever, a viral disease transmitted by mosquitoes, is endemic. Treatment of the annual dengue fever epidemics absorbs much of the health care resources. Chronic otitis media is prevalent in young children.

Services for Children with Hearing Loss

Educational Services. Information concerning the incidence or prevalence of hearing loss is difficult to obtain. The Gallaudet Research Institute, in its Annual State Survey, has pages of zeros for numbers and percentages of deaf and hard-of-hearing children in American Sāmoa. A literature search produced only one article on prevalence of hearing loss in Western Sāmoa.

About a dozen deaf and hard-of-hearing children are currently being served under IDEA in American Sāmoa. However, this number of children served under IDEA provides little information about the total number of children in American Sāmoa who are deaf or hard of hearing. Many older children have dropped out of school. Families who are able to do so send their children with disabilities to live with relatives in Hawai‘i or on the U.S. mainland in hopes of receiving more adequate services.

One school in the American Sāmoa school system serves deaf and hard-of-hearing children from preschool through grade six, using American Sign Language. The classroom does not have a FM system. Very few of the children have been provided amplification. This self-contained classroom is located at a large elementary school and provides opportunities for inclusion during lunch and recess. In 2007, a secondary classroom was established.

The classrooms are staffed by teachers who have completed the certificate program in American Sāmoa. None are trained teachers of the deaf. One student from American Sāmoa completed a master’s degree in deaf education at the University of Hawai‘i and currently provides early intervention services through the Part C program. American Sāmoa does not have a certified sign-language interpreter.

Part C Screening. In 2006, the Part C coordinator initiated a hearing screening program for all children referred to the Part C program. Oto-acoustics emissions screening equipment was

purchased, and audiologists were recruited from the mainland to provide training. The Part C program also initiated with LBJ a policy to waive the ■■■ co-payment for families referred for an ENT assessment. However, even with the waiver of the co-payment, many families cannot make the co-payment for prescribed medications, a cost that cannot be covered by the Part C program. These families see the doctor and obtain a prescription. But because the family is unable to pay for the prescription, the baby's medical status and hearing loss remains unchanged

ENT Services. ENT services are provided by a Medical Officer who received additional training to specialize in providing ENT services. Most of the services provided are clinical with almost no surgical services. Global ENT Outreach has worked with the LBJ Administration to provide services on an annual basis. Recently, an ENT surgeon had to be flown from Chicago to provide life-saving surgery on an eight-year old child with acute mastoiditis. The LBJ is in the process to trying to recruit an ENT physician from Fiji.

Diagnostic Audiology. As a result of the two- three-year HRSA grants, audiological resources have increased substantially. During the first three-year grant, a new audiological test booth was installed, and equipment was obtained for pediatric diagnostic evaluations. During the second three-year grant, state-of-the-art diagnostic and screening equipment was obtained. A community-based facility was renovated to provide a sound-treated room for rescreenings and for pediatric audiological evaluations.

Personnel resources consist of a locally trained audiometrist who provides services for older children and adults. Under the HRSA grants, resources were allocated for quarterly visits by a pediatric audiologist.

Speech-language Pathology. Under Part B of IDEA, there is no speech-language pathologist to provide services. The Part C program has contracted for a speech-language

pathologist to come quarterly from California State University, Sacramento to provide evaluations and follow-up assessments. She works with a speech-pathologist assistant (trained under a program operated by the University of Hawai'i Center on Disability Studies) to provide intervention activities between visits. A webcam video conferencing system is being established to improve options for monitoring and consultation.

Parent Support/Advocacy Groups

American Sāmoa does not have a parent group specifically for children with hearing problems. Additionally, American Sāmoa does not have a chapter of *Family Voices*. A Community Parent Resource Center has been funded for American Sāmoa, headed by a parent of a child with an autism-spectrum disorder. There is no IDEA-funded Parent Training Institute (PTI) in American Sāmoa. The newborn hearing screening program has been unsuccessful in establishing a Chapter of Hands and Voices in American Sāmoa.

Summary of Needs

American Sāmoa, located such a long 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 significant permanent hearing loss to develop communication and academic skills commensurate with their hearing counterparts. Geographic, resource, and bureaucratic barriers remain. However, as shown in following sections, those barriers have been reduced. The needs are great, and the challenges enormous, but the opportunity remains auspicious.

RESPONSE

METHODOLOGY

Description of State EHDI Program

In 2008, the Part C “*Helping Hands Program*” took the leadership to establish the EHDI program (called *Ulua’i Laona*). The American Sāmoa Department of Health (DOH) is the lead agency for Part C in American Sāmoa. The first three-year grant was administered by the DOH. Due to numerous administrative challenges, the Director of Health in 2011 asked the Center on Disability Studies (CDS) at the University of Hawai‘i to apply for the second three-year grant as the de-facto agent for the DOH. The DOH is again asking that the CDS apply as the de facto agent for the third three-year grant application. Administration of the Part C program will remain unchanged.

Screening activities are conducted seven days a week, fifty-two weeks a year by the *Ulua’i Laona* staff at the LBJ, the only birthing facility. Although enabling legislation was initially planned, members of the legislature determined that such legislation was not needed—the Department of Health had regulatory authority to establish newborn hearing screening as the standard of care at the LBJ. This program has continued to work well. Parents may decline the screening if they wish.

The initial screen consists of oto-acoustics emissions (OAE) screening. Babies who do not pass initial screening are referred and are scheduled for an OAE rescreening one week following hospital discharge. Follow-up screening is accomplished by a variety of means, including scheduling babies to come to the Helping Hands Office, seeing the babies during well-child visits, or making home visits. For babies who are referred following the second OAE screening, automated auditory brainstem response (AABR) testing is provided. The AABR equipment was purchased two years ago to reduce the refer rate for diagnostic audiology. The

NCHAM audiologist for the region, Dr. Yusnita Weirather, came to American Sāmoa to provide training for the staff in using the new equipment. Children who are referred following the two OAE screenings and the AABR are scheduled for evaluation during the next visit by the pediatric audiologist.

Audiological diagnostic evaluations are provided quarterly at the LBJ by mainland pediatric audiologists contracted by the EHDI program. A child with any degree of hearing loss is eligible for Part C services. Because of the potential delay in obtaining audiological evaluation, and the possibility that the child has a significant hearing loss, children who refer after two screens are given provisional Part C eligibility and receive services to enable their families to begin developing the child's communication skills.

American Sāmoa has received two CDC grants. During its first three-year grant, American Sāmoa completed a tracking system called *SILAS I*—core sections of the grant and a data form framework. This framework included the login and security framework, pick list framework, person framework, and the overall status, phases, activities and outcomes framework. Also added in year two of the first grant was Electronic Birth Certificate functionality, following the 2003 edit specifications for the smaller subset of data used by the Vital Records Office. In year three of the first grant, EHDI functionality was added, with following features: initial newborn hearing screening; identifying children who were missed; re-screening in the hospital; follow-up screening; audiological evaluation; and progress notes. In addition, queues for upcoming activities were created. The queues showed pending activities in priority order and could be sorted by clicking on any of the data headers. Additional queues were created for initial newborn screenings, follow-up screenings, and audiological evaluations. EHDI/Helping Babies Hear went “live” on February 2, 2011.

American Sāmoa is in the third year of a five-year CDC grant to develop a surveillance and tracking system called *SILAS II*. (Although *SILAS II* is still under development, in the discussion below, the two systems are referred by the single name SILAS.)

SILAS tracks all inpatient and outpatient screenings, diagnostic evaluations, ENT visits, Child Find efforts, and activities for treatment and follow-up once a hearing loss has been identified. The EHDI program can submit referrals through *SILAS I* and the Part C staff can access the EHDI referral and view the appropriate EHDI activity. The Part C program in SILAS can view referral activities as well as EHDI program activities in read-only mode. The dashboard has ‘queues’ of all work in progress to help staff manage their work and to help managers monitor progress. To increase end-user performance, the hosting environment was recently moved from the East Coast of the U.S. mainland to Hawai‘i.

Upon completion of initial screening, data are entered into the EHDI data system, using the hospital ID number—a unique identifier for virtually every person in American Sāmoa. These data include initial screening results as well as demographic and medical information. The EHDI coordinator meets weekly with hearing screeners to review data on children born, children who received the initial screening, children needing follow-up screening, and children needing an audiological evaluation. The EHDI coordinator and the SILAS project manager run periodic reviews on the data system and also conduct monthly verification to ensure that all babies who are listed on the LBJ Nursery Log have received hearing screening prior to discharge.

The goals and objectives listed below have been developed to meet program requirements and expectations, to address the challenges experienced during the previous grants, and to be responsive to the unique needs of the territory..

Methodology: Goals and Objectives

Goal 1: Maintain and improve the Newborn Hearing Screening Program by adopting a Model for Improvement to identify where quality improvement is needed in the newborn hearing screening program to meet the 1-3-6 objectives.

1.1 Maintain the current screening, diagnostic and early intervention program to meet 1-3-6 objectives.

1.1.1. Maintain 7-day a week, 52 weeks a year newborn screening services.

1.1.2. Ensure that pediatric audiological services are provided at least three times a year.

1.1.3. Continue collaboration with Helping Hands to provide early intervention services to all identified and referred infants.

1.2 Establish a Quality Improvement Team.

1.2.1 Identify the team members.

1.2.2 Set up a meeting schedule.

1.2.3 Craft an aim statement.

1.3 Review all available program data to identify areas where improvement is needed

1.3.1 Identify what the team needs to accomplish.

1.3.2 Determine outcome measures for measuring improvement.

1.3.3 Make appropriate changes in procedures to incorporate changes.

1.3.4 Monitor continually the data to ensure improvement continues to occur.

Goal 2: Reduce loss to follow-up at all stages of the process to ensure that all babies born with a significant hearing loss are served.

2.1 Expand early childhood hearing screening to day-care facilities and preschools in the community.

- 2.1.1. Identify all day-care facilities and preschools.
 - 2.1.2. Hold a training session for the directors of day-care facilities and preschools to discuss importance, procedures, and follow-up.
 - 2.1.3. Develop a screening schedule that will provide at least semi-annual screening at each of the day-care facilities and preschools.
 - 2.1.4. Expand the *SILAS II* data system to capture data on children identified with a hearing loss in the day-care facilities and preschools.
- 2.2 Extend early childhood hearing screening to include WIC clients.
- 2.2.1. Meet with WIC staff to develop policies and procedures.
 - 2.2.2. Develop a screening schedule that will provide monthly screening at WIC Clinics.
 - 2.2.3. Expand the *SILAS II* data system to capture data on the children identified with a hearing loss in the WIC Clinics.
- 2.3 Collaborate with home visitation program established under the Affordable Health Care Act.
- 2.3.1. Work closely with the Maternal and Child Health program as they adopt an evidence-based home visitation model for American Sāmoa.
 - 2.3.2. Incorporate follow-up to identify children in the program who may have been lost to follow-up.
 - 2.3.3. Explore whether the *SILAS II* system can be expanded to include the children in the home visitation program.
- 2.4 Collaborate with the Head Start program to identify children who may be lost to follow-up.
- 2.4.1. Work with the Head Start program to support their hearing screening activities.
 - 2.4.2. Develop a memorandum of understanding to identify children in the Head Start program who may have been lost to follow-up.

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

3.1 Continue advocacy with pediatricians and LBJ administration for implementation of newborn metabolic screening.

3.1.1 Search for resources to fund the program.

3.1.2 If funding becomes available, develop policies and protocols for the screening process.

3.1.2 If funding becomes available, identify personnel and procedures for the follow-up of positive screens.

3.1.3 If funding becomes available, expand the *SILAS II* data system to capture the data for newborn metabolic screening.

3.2 Work to reduce the prevalence of chronic middle ear disease.

3.2.1 In collaboration with the ENT and Pediatric Departments at the LBJ develop protocols for the medical and surgical management of middle ear disease.

3.2.2 Develop informational materials for families on the prevention of middle ear disease.

3.2.3 Utilize public media for information to the general public on the prevention of middle ear disease.

3.3 Seek additional options for amplification for children with permanent hearing loss.

3.3.1 Make portable amplification units available on a loan basis.

3.3.2 Improve access to individual hearing aids.

3.3.3 Seek opportunities for cochlear implants for children in American Sāmoa.

3.4 Expand support resources for parents.

3.3.1 Support establishment of a Hands and Voices Chapter in American Sāmoa.

3.3.2 Explore opportunities to develop a PTI for American Sāmoa.

WORK PLAN

The work plan, contained in Attachment 1, outlines activities to achieve the objectives and goals, a timeline, the responsible staff member, and the indicator for success.

RESOLUTION OF CHALLENGES

The program was very successful in resolving challenges experienced during the first three-year grant and during the second three-year grant. The following resources are now in place: a highly qualified, dedicated staff; resources for providing diagnostic services; a strong early intervention program; and a data system available to monitor all aspects of the program.

The EHDI Champion for American Samoa, Dr. James Marrone, has been a tremendous asset to the program. He regularly attends the national EHDI meeting and is supportive and helpful to the local program.

Dr. Wendy Switalski, a pediatric audiologist from Michigan, continues her strong commitment to the program. She has been coming regularly to American Sāmoa for more than six years. The continuity she provides to children, their parents, the staff, and community has been outstanding. A second audiologist, Annabel Anae, Sāmoan by birth, has been recruited to become proficient in pediatric audiology in order to provide further audiological continuity for the program.

The greatest challenge remaining for the program is the question of sustainability. As long as federal funds are available, a strong program will continue. But with the limited resources of the local government, it is feared that, without those resources, the program will cease to exist. That would be tragic!

EVALUATION AND TECHNICAL SUPPORT CAPACITY

The evaluation plan will comprise an ongoing monthly process to constantly enable the program to assess the progress of the activities in achieving the objectives and accomplishing the goal. Monthly assessment will enable the program to refine, reassess, and redirect resources based on what is working well and what is not working well. The commitment is to develop a visionary system for American Sāmoa whereby all young children with special needs are identified and, through tracking, receive follow-up and intervention services needed. The goal is to eventually be able to measure outcomes from intervention services.

Plan for Monitoring Process Indicators

The Ministry of Health has entrusted management of this grant to the Center on Disability Studies to improve management efficiency, enabling the project to successfully achieve its goal and objectives. Annual monitoring of the increased efficiency of processing contracts and payments and recruiting personnel will be provided. Improved capacity for meeting federal reporting requirements is another positive result of changing the management arrangement. Process indicators will be monitored annually, and a written report sent to the Director of Health in American Sāmoa.

Plan for Monitoring Health Performance Indicators

The *Ulua'i Laona* logic model, as diagramed in Figure 2, will drive the evaluation process. The five-year CDC Grant for continued development *SILAS II*, a comprehensive surveillance and tracking system for early hearing detection and intervention, will be used to monitor monthly the following indicators.

- What percentage of babies received an in-hospital screening? (This indicator will require having the monthly number of in-hospital births.) If this number ever falls below 95%,

discussion will be needed with the EHDI Coordinator to determine why this decline is occurring and to provide a solution.

- What was the initial hearing screening refer rate? The goal is for this number to be lower than 8%. 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 is needed.
- What was the rescreen refer rate? The goal is to have this number no higher than 1%. If the rate begins to exceed this percentage, possible causes will be examined and changes made to reduce the rate as much 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 percentage as close to zero as possible.
- How many out-of-hospital births occurred and what percentage of those babies received hearing screening by one month of age? The goal for this measure is 100%.
- How many babies received an audiological diagnostic evaluation by three months of age? This indicator continues to be one of the most problematic. Even with quarterly visits by the audiologists, inevitably a baby will be sick at the time of the visit, meaning another three months before a visit can be scheduled. Chronic middle ear problems in children continue to plague the program, complicating the completion of the diagnostic testing. 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. Many of the plans for expansion of *SILAS II* into the preschool period, coupled with plans for expanding hearing screening to young children in other settings, will assist in identifying those children and eventually providing them an audiological evaluation.

- How many babies with a hearing loss were enrolled in early intervention by six months of age? The goal for this measure is 100%. With the close relationship between the EHDI grants and the Part C program, this percentage is definitely achievable.
- How many babies identified by the newborn hearing screening program are receiving early intervention services? The goal for this measure is 100%.

Monitoring of Additional EHDI Indicators

The indicators in the preceding section are those required under the EHDI surveillance system to meet the basic 1-3-6 goals. However, *SILAS II* is being developed to expand beyond hearing screening to enable more comprehensive tracking of children with special needs. In addition to the above EHDI indicators, *SILAS II* will provide information to enable the evaluation of the following types and outcomes of intervention services.

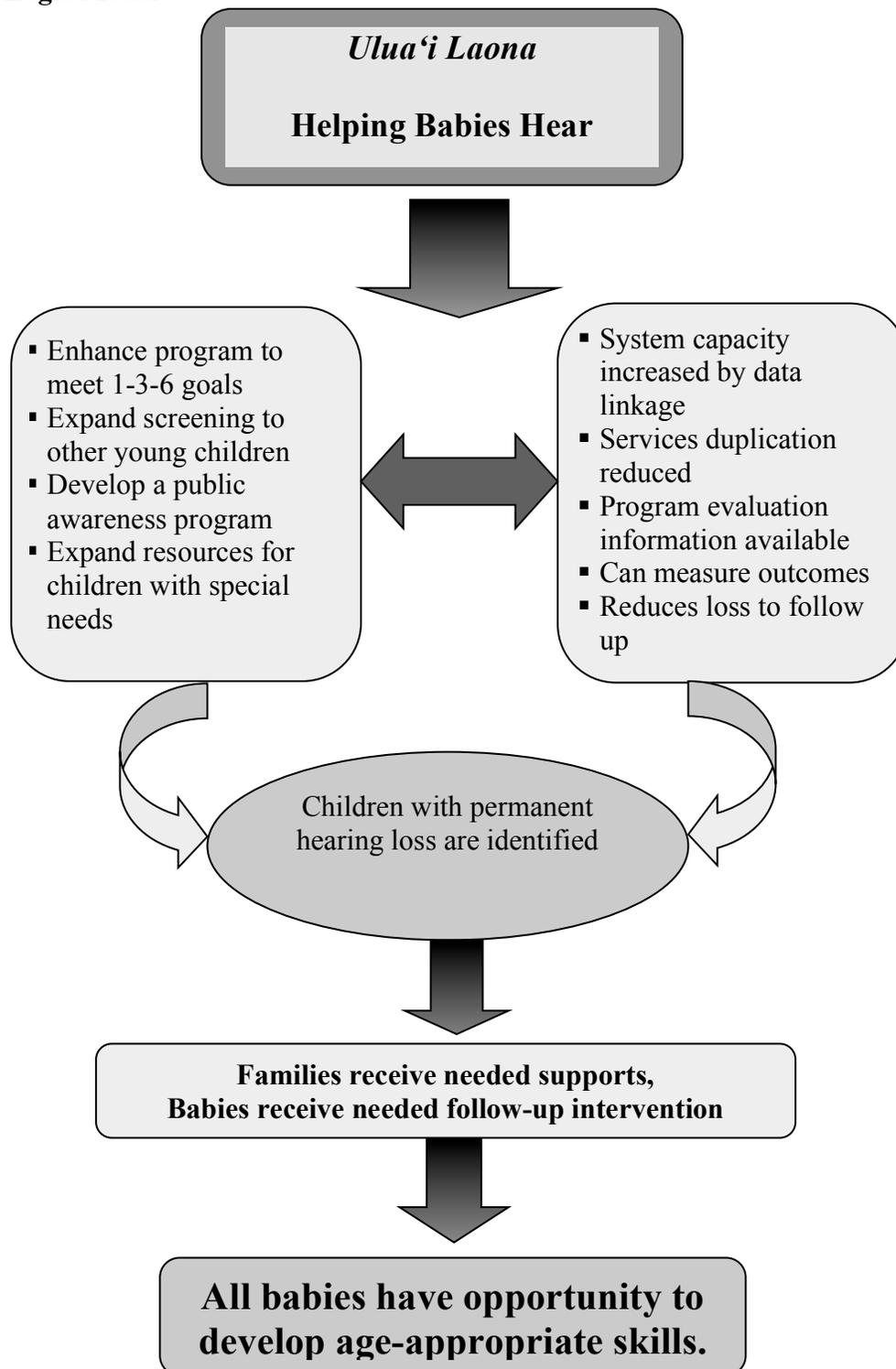
- How many children were provided a means of amplification?
- What were the outcomes of those intervention services as measured by the communication skills of the child and the satisfaction of the families with services?

Process and Output Measures to Assess Timeliness, Completeness and Impact

The Evaluation Table outlines the activities that will be undertaken to accomplish each of the objectives. Shown in the table are the responsible person, 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 assess status, will work with the project to overcome encountered barriers, and will identify resources to assist the project in meeting any challenges it is encountering. The evaluation will be discussed during regularly scheduled monthly Skype discussions with the Project Manager, EHDI Coordinator, and Part C Coordinator.

Figure 2: Logic Model

Impact

Newborn Metabolic Screening. In every other state and territory, universal newborn metabolic screening existed before implementation of newborn hearing screening programs. New programs were encouraged to build on the existing screening and follow-up programs and to merge their databases whenever possible. This is not the situation in American Sāmoa. No universal screening is done for newborn metabolic disorders. Instead, pediatricians refer babies for specific screening when the pediatricians suspect a problem. Often too much time has passed to provide beneficial intervention.

The newborn hearing screening program has already had an impact on quality of services to newborns. The project staff met with the CEO of the LBJ and the Chief of Pediatrics to discuss the importance of implementing newborn metabolic screening. During the first three-year *Ulua'i Laona* grant, the evaluator wrote a proposal to implement newborn metabolic screening utilizing funding by the American Reinvestment and Recovery Act (ARRA). Although that proposal was approved, funds were never provided. Meetings were arranged at each of the annual EHDI meetings to meet with the Director of the National newborn Screening and Genetic Research Program to develop strategies for achieving implementation.

Although funding has not been forthcoming, the LBJ Pediatric Department did identify a pediatrician to oversee the program. The Principal Investigator provided support for the pediatrician to come to Hawai'i in 2012 to meet with the Newborn Screening Program and geneticists in Hawai'i to develop a protocol and process for implementing the program. Unfortunately, shortly thereafter, the pediatrician left American Sāmoa for a position in Alaska. Changes in the administration at the LBJ and various fiscal crises that were encountered reduced priority for implementing this program.

Pediatric Audiology. Similarly, 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 American Sāmoa. As a result of the first *Ulua'i Laona* three-year grant, a new auditory testing booth was purchased and installed at the LBJ. State-of-the art audiological equipment has been purchased. Although the primary purpose for these clinical enhancements was to ensure diagnostic capacity for babies identified during the newborn hearing screening program, these resources are also available to expand capacity for all children and adults with hearing loss.

The dispensing of hearing aids is expanding as a result of the newborn hearing screening program. Collaboration is occurring with Solar Ear to make low-cost hearing aids and solar-powered batteries available to children and adults in American Sāmoa. At the present time, communication options for families are very limited. Cochlear implants have not yet been seen as a viable option. But over time, this will change.

Dissemination of Results

The results of the newborn hearing screening program have been widely disseminated through regional, national, and international meetings. Presentations have been made at five Pacific Rim International Conferences on Disabilities. Additionally, presentations have been made at the Conference of the American Association of University Centers on Disabilities in Washington, DC, at the American Public Health Association Meeting, the Division of Early Childhood of the Council on Exceptional Children, and the International Society for Early Intervention Conference. In 2012, a presentation was made at the Newborn Hearing Screening Conference in Lake Como, Italy. Also in 2012, a poster on the program won the “Best Poster” prize in Bad Ischl, Austria during the First Annual Conference on Family Centered Early

Intervention for Children Who are Deaf or Hard of Hearing. In 2011, the work being done in American Sāmoa was highlighted during Mekong Sante in Phnom Penh, Cambodia, creating interest in beginning newborn hearing screening in Cambodia. Most recently, a presentation was made at the August 2013 Conference of the International Association for the Scientific Study of Intellectual Disabilities in Tokyo, Japan. (All costs for international travel for dissemination were paid from personal funds, not grant funds.)

In May 2013, a presentation was made at the 4th Annual Coalition for Global Hearing Health held at Vanderbilt University in Nashville, Tennessee. This presentation provided an opportunity to try to recruit ENT fellows to donate time in American Sāmoa. The conference also provided a linkage for the purchase of low-cost hearing aids.

An article, “American Sāmoa Embraces Newborn Hearing Screening,” was published in the June 2012 issue of *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 American Sāmoa during the first year. Samples of articles are in the Attachments.

Replicability and Sustainability

The challenges facing establishment of a universal newborn hearing screening program in American Sāmoa are very much like those that would be faced by many of the nations in Oceania. The independent nation of Sāmoa, with a population of almost 200,000, is only 60 miles away. Neither newborn hearing screening nor newborn metabolic screening are being done there. The Kingdom of Tonga is another Pacific neighbor. Addressing the challenges and establishing a viable, sustainable program in American Sāmoa could provide a model for replication elsewhere in Oceania.

ORGANIZATIONAL INFORMATION

Capacity and Infrastructure

For the first three-year grant, infrastructure capacity was the greatest challenge in implementing newborn hearing screening. Delays in the processing of contracts and delays in recruitment of personnel reduced the project's capacity to achieve its outlined objectives. These challenges were further exacerbated by a tsunami that devastated parts of American Sāmoa in late September 2009. Key personnel from the Helping Hands (Part C) Program were reassigned to assist with helping American Sāmoa citizens who were experiencing post-traumatic stress disorder following the tsunami. Also, new procurement policies were put in place. Whereas previously the Part C Program had been able to contract directly for audiological services, a new request-for-proposal process was instituted that resulted in a 20-month gap in provision of audiological services.

To address these bureaucratic challenges, during the third year of the first three-year grant, contract amendments were processed to enable the Center on Disability Studies (CDS) at the University of Hawai'i to administer the bulk of the funds under the grant. This new arrangement has worked exceedingly well.

Subsequently, the CDS was asked to submit an application for the second three-year grant as a "bona-fide agent" for the American Sāmoa Department of Health. This arrangement enabled the newborn hearing screening program to work much more efficiently and effectively. This arrangement is feasible because a faculty member of the CDS, Assistant Professor Dr. Jean Anderson-Asuega, works on-site in the Helping Hands Program in the Department of Health in American Sāmoa. In that capacity, she serves as the link between the program in American Sāmoa and the Principal Investigator in Hawai'i. Consequently, based on this success, the DOH

has again asked the CDS to apply as the bona fide agent on behalf of American Sāmoa. A copy of the letter from the Director of Health is in Attachment 4.

Staffing and Management Plan

Resumes for the following personnel who will be involved in the project are in Attachment 3. Position descriptions are also included in Attachment 2, along with an organizational chart for the program in Attachment 5. All the following personnel have extensive experience in the implementation of newborn hearing screening and tracking activities.

Principal Investigator (0.10 FTE). Dr. Jean Johnson will serve as Principal Investigator of the project, overseeing the administration activities and implementation of the project for American Sāmoa. Dr. Johnson has been involved with the program since its inception, having assisted in writing the original grant, and providing technical assistance and project evaluation. She will coordinate closely with the EHDI Coordinator in American Sāmoa on all decisions about staffing, contracting, and purchasing.

EHDI Coordinator (0.50 FTE). The EHDI Coordinator for the program will be Dr. Jean Anderson-Asuega, a clinical psychologist by training. Dr. Anderson-Asuega was the Part C Director 2004-2010. During that time, she incorporated hearing screening into the Part C Program. She holds a concurrent appointment as Assistant Professor with the CDS. Dr. Anderson-Asuega has been the EHDI Coordinator since the beginning of the program.

Program Manager (0.50 FTE). Ms. Bethany Toulupe was recruited in 2011 to serve as the Program Manager. In this capacity she provides direct supervision for the hospital screeners, oversees the rescreening process, and ensures that appropriate data entry takes place. She fills in at the LBJ for the screeners when they may be on sick leave or vacation leave.

Administrative/Fiscal Support (.25 FTE). Ms. Juana Tabali-Weir will continue to provide administrative and fiscal support for the project as she has for the past four years. She processes personnel actions, travel papers, purchase orders, and payments. She also maintains the equipment inventory.

Management Plan

The organizational chart for the project is in Attachment 5. The personnel will remain unchanged from the current three-year grant. The CDS will administer the project in collaboration with the Helping Hands Program. The Part C Program will continue to provide space to the project staff. Another key member of the EHDI Team (Ms. Ruth Te‘o) is the Part C Coordinator for American Sāmoa. Ms. Te‘o served as the program supervisor over the past three years and is a highly competent newborn hearing screener. She has participated in four national EHDI meetings.

The EHDI Coordinator located in American Sāmoa will serve as coordinator between the Part C Coordinator, local staff, and the Principal Investigator in Hawai‘i. Communication will largely be by email. However, the Principal Investigator in Hawai‘i and the staff in American Sāmoa have Skype capacity to enable “person-to-person” communication for regular management meetings and whenever a special need arises. Because this management team has worked together now for six years, it is no longer necessary to budget funds for the Principal Investigator to make site visits to American Sāmoa.

LIST OF ATTACHMENTS

Attachment 1 – Work Plan

Attachment 2 – Staffing Plan and Job Descriptions for Key Personnel

Attachment 3 – Biographical Sketches of Key Personnel

Attachment 4 – Letters of Agreement and/or Descriptions of Proposed/Existing Contracts

Attachment 5 – Project Organizational Chart

Attachment 6 – Tables, Charts, etc.

Attachment 7 – Summary Progress Report

Attachment 8 – IDC Agreement