

Project Narrative

▪ INTRODUCTION

The Federated States of Micronesia (FSM) intends, through this opportunity, to continue its successful efforts in the Early Hearing Detection and Intervention (EHDI) system as evident by the improved rates of diagnostic audiology evaluation (DAE) services and referral to early intervention (EI) services. According to the most recent data from January 2018 to June 2019, 60% of infants referred received DAE by three (3) months of age and 100% of those with documented hearing loss were referred for EI services. In past years, both these measures were 0%.

FSM implemented teleaudiology in 2018 despite incredible challenges such as the expansive oceanic service area, delays in availability of high speed internet access, budget limitations to supporting all four States, and disruptions in equipment acquisition and training. However, with the addition of teleaudiology in the two most populous states, FSM has been able to provide timely DAE.

In the past, FSM struggled with provision of timely early intervention services for infants identified with hearing loss, by six (6) months of age. Because FSM does not qualify for Part C, the DAE was critical for development of the Infant Family Service Plan (IFSP) under Special Education (SpEd). Babies can be referred for early intervention and be monitored, but no IFSP can be developed unless the baby has a diagnosis of hearing loss by a certified audiologist. With timely teleaudiology and the addition of a licensed speech and language therapist to the learning community, EI has improved. FSM continues to provide early intervention training for Related Services Assistants (RSAs) to continue to upgrade skills in working with families with infants identified with hearing loss and to work collaboratively with Special Education in services for all infants with disabilities in the FSM.

In addition, much has been done since 2015 to improve the quality and success of initial screening to further reduce failed initial screening (FIS) rate to 4.5% and therefore reduce the number of infants that have the risk to be lost to follow up. This rate had been upwards of 30% in 2012 and 12% in 2015. These reductions by more than half continued in the last three years.

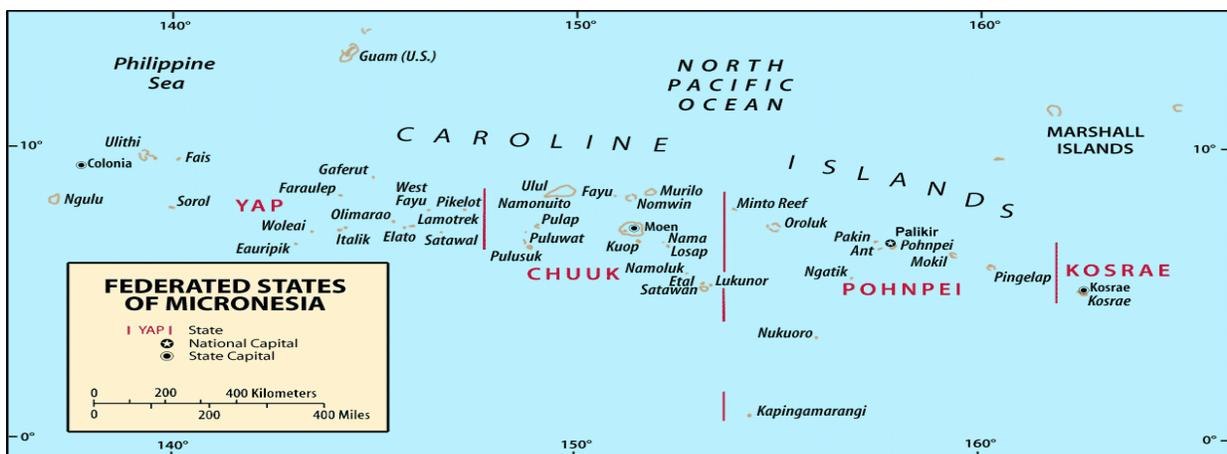
Even with these current and effective activities to increase diagnostic and early intervention services, there are still gaps in the FSM EHDI program similarly identified by the HRSA EHDI program in this funding announcement. Therefore, FSM is pleased to utilize the reformed HRSA EDHI program guidance to improve the FSM program through utilization of this funding. The purpose is to support the comprehensive and coordinated EHDI system of care so families with newborns, infants, and young children up to three (3) years of age who are deaf or hard-of-hearing (D/HH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention. This purpose will be achieved by focusing actions to: 1) Lead efforts to engage all EHDI system stakeholders at the state/territory level to improve developmental outcomes of children who are D/HH; 2) Provide a coordinated infrastructure to ensure that newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI by 6 months of age and reduce loss to follow-up/loss to documentation; 3) Identify ways to expand state/territory capacity to support hearing screening in young children up to 3 years of age; 4) Strengthen capacity to provide family support and engage families with children who are D/HH and adults who are D/HH throughout the EHDI system; 5) Engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations; the need for hearing

screening up to age 3, the benefits of a family-centered medical home and the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to families to facilitate the decision-making process; and 6) Facilitate improved coordination of care and services for children who are D/HH and their families through the development of mechanisms for formal communication, training, referrals, and/or data sharing.

FSM proposes to build upon the successes of the last three years to further strengthen the collaborative EHDI program team to ensure that newborns are screened by one (1) month of age, diagnosed by three (3) months of age, and enrolled in EI by six (6) months of age and reduce loss to follow-up/loss to documentation to ultimately improve developmental outcomes of children who are D/HH. FSM will utilize these past successes to expand the program for children up to age three (3). The details of the proposed FSM EHDI program are described in detail in the following sections.

▪ *NEEDS ASSESSMENT*

To understand the challenges and context of the Federated States of Micronesia (FSM), which have been overcome to some extent, to develop and implement an EHDI program, a brief review of the geographical location, political status, population, and the significant ethnic and linguistic diversity of the FSM is necessary. The FSM is an island nation with a total population of approximately 103,000 spread out over some 607 widely dispersed islands in the Western Pacific Ocean. The FSM is a constitutional federation incorporating four main states: Pohnpei, Chuuk, Yap and Kosrae. Kosrae State is the only FSM State composed of a single island. Surrounding each of the other three States are sparsely inhabited outer islands. Each of the FSM States are separated by hundreds of miles of Pacific Ocean accessible only by airplane or boat. In the map below, the many islands of Yap, Chuuk, and Pohnpei State can be appreciated. The FSM National Government offices are located on the largest island of Pohnpei. It is from Pohnpei that overall FSM governmental operations are coordinated with the four States of the FSM.



Politically, the FSM is a freely associated nation with the United States under a Compact of Free Association entered into with the United States in 1986 with an amended compact entered into on June 30, 2004. Each of the four FSM States has its own constitution, elected legislature and governor. The governments of the FSM and the United States maintain deep ties and a

cooperative relationship, with over 25 U.S. federal agencies that maintain programs in the FSM.

The people of the FSM are highly diverse with nine main and different ethnic groups speaking some thirteen (13) different languages. Table 1 presents the ethnic groups in the FSM, and percentage of individuals at each location by State. From Table 1 it can be noted that the dominant ethnic group in each of the FSM States are the native population to that island state, i.e. 96% of the Chuukese/Mortlockese people reside in Chuuk State. Also note that the Asian population resides primarily in Yap State and Pohnpei State, while the small population of Whites are predominately in Pohnpei State.

Table 1. Location of Each FSM Ethnicity Group Across the States¹

Ethnicity Groups in the FSM	Total	Yap State	Chuuk State	Pohnpei State	Kosrae State
Yapese	5,752	95.9%	.4%	3.4%	.3%
Yapese/Outer Island	4,126	99.3%	.1%	.6%	---
Chuukese/Mortlockese	52,268	.4%	96.2%	3.3%	.1%
Pohnpeian	25,855	.1%	.2%	99.4%	.3%
Kosraean	7,169	---	.2%	3.3%	96.5%
Polynesian/Caucasian	1,496	.2%	.5%	98.7%	.6%
Asian	1,265	42.4%	4.3%	49.2%	4%

This highly diverse population with different languages or dialect use English to communicate across the four FSM states. English proficiency levels vary, with most of the older population being monolingual in their own native language or bilingual in another language, e.g. Japanese. Most of the younger population has basic English proficiency skills. In the FSM classrooms, children are taught in both their native language and English from first to third grade, after which English is used almost exclusively in middle-elementary to high school. What is truly unique about the linguistic context of the FSM is that each major language is not interrelated with the other language. Each has its own linguistic structure, pronunciation, vocabulary, sentence structures, and semantic, syntactic, and pragmatic rules. For example, when a bilingual citizen of the FSM who speaks Pohnpeian interacts with an individual who speaks Kosraean, the common language used between them will be English, since there are no common linguistic features between Pohnpeian and Kosraean, each is distinctly different from the other. Within the population, it is not uncommon for FSM citizens to be proficient in two or more languages; most are bilingual, many are trilingual, and some speak four or more languages. With the arrival of many Asian businesses to the FSM, other languages are being introduced, such as Filipino and Chinese. Health literacy across all inhabitants is low as higher education is not common in FSM.

The EHDI Program respects this cultural and linguistic diversity and seeks appropriately paired demographics within its staff, community leaders and families that participate in the program on each island state. In addition, EHDI Program staff are proficient in relaying health information in easy-to-understand vernacular.

¹ Source: Federated States of Micronesia: 2000 Population and Housing Census Report, May 2002. Division of Statistics, Department of Economic Affairs FSM National Government

Table 2 clearly demonstrates the improvement at all levels of screening since the addition of electronic health records to more accurately capture the true data, teleaudiology in two states to reduce wait time for diagnostics, and a speech and language pathologist to provide early intervention.

Table 2. Screening Rates and Loss to Follow-Up in the FSM Comparing 12 months Calendar Years 2015 and 2018

FSM TOTALS	2015	2018	Difference
Total Births	1752	1760	8
Total Screened before hospital discharge or by 1 month	1398	1412	
Screening Rate	79.8%	80.2%	0.4%
Total Infants LFU for Initial Screening	354	253	
Percent LFU for Initial Screening	20.2%	14.4%	5.8%
Total Infants Failed Initial Screening (FIS)	169	67	
FIS Rate	12.1%	4.5%	7.6%
Total Infants Needing Rescreening	169	67	
Total Infants Rescreened	36	44	
Total LFU for Rescreening	133	23	
Percent LFU for Rescreening	78.7%	34.3%	44.4%
Total Infants Needing DAE	169	5	
Percent LFU for DAE	100%	40%	60%

As apparent in Table 2, although the screening rate has stayed the same during this past grant cycle, effectiveness of screening has improved as the total failed initial screening rate has decreased 7.6%. A more effective initial screening prevents the need for as many follow ups which puts children at risk for loss to follow up. This can be seen by the loss to follow up for initial screening has improved 5.8%. In addition, the total infants requiring rescreening has greatly decreased making the risk of lost to follow up for rescreening less. The program greatly improved its loss to follow up for rescreening by decreasing it 44.4%. The largest improvement can be seen in the percent loss to follow up for DAE reduced by 60%.

Table 3. 1-3-6 Recommendation Compliance in the FSM Comparing 18 months July 2016-December 2017 and January 2018-June 2019

FSM TOTALS	July 2016-December 2017	January 2018-June 2019
Total births	2596	2289
Percent screened by 1 month	83.9%	80.7%
Percent received DAE by 3 months	0%	60% (3/5)
Percent referred to EI by 6 months	0%	100% (1/1)

Table 3 describes the compliance with 1-3-6 recommendations during last eighteen (18) months of the current grant cycle and the previous eighteen (18) months prior to that. Again, although the data does not show an improvement in screening itself, it depicts significant improvements in DAE and EI. Until these past eighteen (18) months, no infant was meeting compliance with the three (3) and six (6) month recommendations due to lack of DAE services, explained in more details below in (1). Since 2018, all three of the three infants in Pohnpei requiring DAE received

it, two infants are awaiting DAE in Chuuk and no infants were referred for DAE in Kosrae or Yap. Of the three infants that received DAE, two passed and one was identified with hearing loss. That one child was enrolled in EI immediately which was before the six (6) month recommendation. Of important note related to screening, an additional data point was added to the EHR to record remote outer-island births. When these births were removed from the total births, the screening compliance increased to 92.4%, explained in more details below in (4).

The following explains some of the strategies implemented and to be continued to reduce barriers to screening and recommended follow up services.

(1) DAEs were being completed, but not always in a timely manner, by three (3) months of age, due to no audiologist in all of FSM and the cost and lengthy enactment process of teleaudiology. In 2018, teleaudiology was established and fully implemented in two states, Pohnpei and Chuuk, allowing the most populated states to be able to avail of DAE through teleaudiology. This project, while slow and expensive in development has and will continue to improve the DAE of infants. The continuation of the contract with Global Impact Audiology will provide infant DAE via tele-audiology in Chuuk and Pohnpei states. A contract with Guam Hearing Doctors will allow for on-site audiology services in Yap twice a year and Kosrae as needed.

(2) The number of infants who fail initial hearing screening is significantly lower than in past years at 4.5% failed initial screening. Further training both on-site with the pediatric audiologist and online options have been explored and utilized to improve this rate. Much focus was directed to continue to improve initial screening success to prevent the need for rescreening. The professional learning community has assisted in this effort by public health, hospital and CHC staff receiving presentations on EHDI related content from highly qualified individuals not available in the FSM. In addition, screening staff and National EHDI Program staff was provided on-going technical assistance to related to screening and follow-up practices.

(3) Provision of timely early intervention services for infants identified with hearing loss, by six (6) months of age are now occurring. Because FSM does not qualify for Part C, the DAE is critical for development of the Infant Family Service Plan (IFSP) under Special Education (SpEd). Babies can be referred for early intervention and be monitored, but no IFSP can be developed unless the baby has a diagnosis of hearing loss by a certified audiologist. FSM-EHDI has entered into Memorandum of Understandings (MOUs) with one of the four FSM States on referrals for children under three (3) and will continue to work with FSM SpEd and State SpEd to finalize MOU agreements and define a protocol for referring infants for early intervention services. Through the teleaudiology, time to DAE was reduced. In addition, the program coordinated all services in the FSM, so that any time a child is identified with any hearing loss, the contracted Speech and Language Pathologist and SpEd are notified to increase the number of infants identified as deaf/hard of hearing (D/HH) that receive some intervention within three (3) months of diagnosis. The learning community increased the capacity EHDI and SpEd staff as well as families through a teaming model by providing family / provider education classes.

(4) Accuracy of documentation was improved to gain a better understanding of screening practices. The EHDI-IS called HER in FSM now tracks the birth of infants on the outer islands of FSM. As described above FSM consists of 607 islands separated by hundreds of miles of Pacific Ocean accessible only by airplane or boat, but only four islands offer health and hospital services including newborn hearing screening. Although not many births (approximately 200/year) occur on these outer islands, these births greatly affect the one (1) month screening data. With the addition of documenting location of birth in HER, the program can analyze and

report that its one (1) month screening rate with this hard-to-reach population removed is 92.4%. This distinction allows the FSM EHDI program to determine focused strategies for improvement on this geographically disparate population.

Although many improvements were made during the last grant cycle, the following explains some of the barriers to screening and recommended follow up services as well as proposed strategies to overcome them.

(1) Difficulty of equipment acquisition and maintenance due to FSM's remote location and severe weather (i.e. humidity and heat) impact. FSM will continue to coordinate with the other Pacific islands for calibration services and continue to monitor equipment maintenance at each state site insuring that equipment is always stored in environmentally appropriate room. The program is studying the feasibility of creating a loaner hearing aid bank so that a child diagnosed with a hearing loss that would benefit from amplification, might be fit within three months of diagnosis so that intervention could be effective and language acquisition can be obtained.

(2) Access and availability of parent advisory and support groups, as more infants are identified. The availability of these groups with access to professionals knowledgeable in the D/HH community needs is important to a healthy outcome for young children. FSM EHDI will organize an EHDI Advisory Committee and will work with FSM SpEd to ensure parents with infants with hearing loss are referred to State Inter-Agency Collaboration (SIAC) parent groups. In addition, language acquisition services will continue to be provided from a licensed speech language pathologist with a background and expertise in deafness.

▪ *METHODOLOGY*

The FSM EHDI Program will implement the activities and strategies proposed in this section to achieve the overall goal of which is to develop a comprehensive and coordinated statewide Early Hearing Detection and Intervention (EHDI) system of care targeted towards ensuring that newborns, infants and children up to age three (3) are receiving appropriate and timely services, including screening, evaluation, diagnosis, and early intervention between April 1, 2020 and March 31, 2024. There are four goals that lead to this overall goal: 1) ensure that infants receive appropriate timely services, including screening, evaluation, diagnosis, and early intervention by leading efforts to engage and coordinate all stakeholders of the EHDI System, 2) engage, educate, and train health professionals and service providers in the EHDI system, 3) strengthen capacity to provide family support and engage families with children who are D/HH as well adults who are D/HH throughout the EHDI system, and 4) facilitate improved coordination of care and services for families and children who are D/HH.

Goal 1: Ensure that infants receive appropriate timely services, including screening, evaluation, diagnosis, and early intervention by leading efforts to engage and coordinate all stakeholders of the EHDI System

The first objective under this goal is to improve the screening rate to 89% or more screened by one (1) month. The 2017 CDC HSFS reported 30-day screening rate was 45%, however at time of reporting the data entry was still lagging. Therefore, for this objective baseline we are using the updated 2017 rate after all data was entered of 85%. This will be accomplished through providing on-going technical assistance to screening staff and National EHDI Program related to screening and follow-up practices, providing educational opportunities to screening staff through attendance at the National EHDI Conference (up to two staff annually), and collaborating with

regional and national programs for educational and training resources.

National EHDI Coordinator with the assistance of State EHDI Coordinators will provide on-going technical assistance to screening staff and FSM National EHDI Program related to screening and follow-up practices. This has been shown to be effective during the last cycle with a much reduced fail initial screening rate. By reducing the fail initial screening rate, the number of children at risk for loss to follow up is reduced. In addition, educational opportunities will be provided to screening staff through rotating attendance to the HRSA National EHDI Conference. Additionally, FSM will seek collaboration with regional Pacific Island Jurisdictions' EHDI Programs to identify educational and training resources as well as educational and training resources through National resources such as the National Technical Resource Center (NTRC) for Newborn Hearing Screening and Intervention, Family Leadership in Language and Learning (FL3) Center and the Leadership Education in Neurodevelopmental and related Disabilities (LEND) program.

The second objective is to improve the diagnostic audiological evaluation rate by three (3) months to 85% or more. This will be accomplished through providing infant DAE via tele-audiology in Chuuk and Pohnpei state and on-site audiology services at least once a year in Yap and Kosrae, if needed.

In 2018, teleaudiology was established and fully implemented in two states, Pohnpei and Chuuk, allowing the most populated states to be able to avail of DAE through teleaudiology. Consequently since 2018, the DAE rate by three months has been 60%. This project, while slow and expensive in development has and will continue to improve the DAE of infants. The continuation of the contract with Global Impact Audiology will provide infant DAE via tele-audiology in Chuuk and Pohnpei states. A contract with Guam Hearing Doctors will allow for on-site audiology services in Yap twice a year and Kosrae as needed.

The third objective is to maintain the early intervention rate by six (6) months at least 80%. This will be accomplished through improving coordination of all audiology services in the FSM, so that any time a child is identified with any hearing loss, the speech and language pathologist and special education are notified as determined by evaluation, EHDI staff will present on EHDI related content presentations to special education staff as needed, and JOY Consulting staff will present at the biennial FSM Interagency Conference.

Provision of timely early intervention services for infants identified with hearing loss, by six (6) months of age are 100% in the past year and a half. Because FSM does not qualify for Part C, the DAE is critical for development of the Infant Family Service Plan (IFSP) under Special Education (SpEd). Babies can be referred for early intervention and be monitored, but no IFSP can be developed unless the baby has a diagnosis of hearing loss by a certified audiologist. Through the teleaudiology, time to DAE is reduced. In addition, the program coordinates all audiology services in the FSM, so that any time a child is identified with any hearing loss, the contracted Speech and Language Pathologist and SpEd are notified to increase the number of infants identified as deaf/hard of hearing that receive some intervention within three months of diagnosis. This proven coordination will be continued to maintain the high rate of enrollment in early intervention.

The activities toward this objective are to evaluate the referral and enrollment process between FSM EHDI, JOY Consulting and SpEd, and build the capacity of families as well as SpEd staff through a teaming model by providing family / provider education classes. EHDI staff will

provide EHDI related presentations to Special Education staff to increase their knowledge and understanding of the importance of early intervention. In addition, JOY Consulting will provide education on early intervention practices at the biennial Interagency Conference. These inter-agency forums are the best venue for broad dissemination of information because they include all partners including clinicians, partner organizations, consultants, families and community organizations.

The fourth objective is to expand infrastructure, data collection and reporting on hearing screening for children up to age three (3). This will be accomplished through expanding data collection and reporting on hearing screening for children up to age three (3), educating program partners on expanded hearing screening up to age three (3), and expand hearing screening to children up to age three (3).

To date FSM has been concentrating efforts on newborn hearing screening. FSM will contract with FamilyTrac, the developer of the current EHDI-IS system locally referred to as HER, to build the capacity to collect data and report on the expanded age range of services. FSM will also educate program partners such as Title V Maternal Child Health (MCH), Children and Youth with Special Health Care Needs and Special Education on this expanded service age and accept referrals for screening. Because the following programs do not exist within the FSM, they are not included as programs in the expansion efforts: Title XIX - Medicaid, Title XXI - Child Health Insurance Program, Part C IDEA, HOME Visiting, Child Welfare Programs, Security Administration, WIC Program, Rehabilitation Services, Newborn Bloodspot Screening, Family-to-Family Health Information Centers, Schools or Offices for the Deaf, State Chapters of the American Academy of Pediatrics or equivalent, Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs or on-island Family Organizations.

The fifth and final objective under this goal is to strengthen program through partnerships, inclusion, evaluation and sustainability. This will be accomplished through convening EHDI Advisory Committee in each State at least annually, maintaining partnerships for referral, training and information sharing, developing a plan to address diversity and inclusion, monitoring and assessing program performance, and increasing the number of FSM States with legislation mandating hearing screening from two to four states through education to promote sustainability.

In the four states, an interagency agreement has been developed that involves the Children with Special Needs (CSHCN) Program including EHDI Program, MCH Program, the State Hospital, the Department of Education, Special Education Program, the Early Childhood Education Program, and the Parent Network. This interagency agreement has been established to assure that children are screened for disabilities, and those who are suspected of having a disability are referred to the appropriate program for an assessment. The agreement also assures that an interdisciplinary team of members from each of the agencies is available to conduct an assessment, develop the individualized plan, and provide or coordinate the services. Each state has an Inter-Agency Council (IAC) consisting of representative from Public Health, Special Education, community groups such as churches, traditional leaders, NGOs and advocacy bodies, as well as parents and consumers of the CSHCN and EHDI services. A Maternal Child Health staff member represents the program on each of the state's Inter-Agency Council. Being that each state has an IAC the diversity of each state's population is represented appropriately. The FSM Department of Education, in particular the Early Intervention Service, is an essential partner of the EHDI Program. Together the agencies offer services for children served by the

FSM Department of Education and the Public Health Program for Children with Special Needs. Each state has established coordinated relationships and linkages among the local Departments of Education - Special Education, Population Education Projects, and Early Childhood Education Program and social services. With the establishment of these inter agency linkages, gaps in communication have narrowed and duplication of efforts has been minimized. However, the current use of the parent/program partnership is limited in the FSM. In Kosrae, the IAC meets monthly and has approximately twenty (20) members, half of which are parents and consumers. In Chuuk, the IAC has blended with the duplicative Special Education Board which had the same association objectives and focus. The Special Education Board meets quarterly and has approximately fifteen (15) members, half of which are parents or consumers. In Yap, the IAC is not very active and attempts to meet quarterly but with difficulty. Only one (1) parent serves on the council. In Pohnpei, the IAC has not met for at least two (2) years. Where the IAC is active, parents and consumers have an equal say and equal vote to other members in the business of the council. Council business centers around patient rights, program policies, access issues, and needs and gaps in services provided. The EHDI program intends to expand its parent/consumer partnership through the EHDI Advisory Committee in the coming years to improve public input into the program and its policies and objectives.

Because of the small size of FSM and the limited healthcare services, the medical home concept is very different in this region. Health services in the FSM are designed and delivered at the State level. At the State level, the Department of Health Services is headed by the Director of Health, who is appointed by the Governor of the State and is responsible for all medical and health services in the state. Each state has a central State Hospital with medical, nursing, and support personnel that provide all of the acute inpatient and outpatient medical services for the residents of the state. With limited facilities and even more limited staff, there are not multiple unrelated facilities where patients receive services. The EHDI Program works with the Pohnpei, Chuuk, Kosrae and Wa'ab (on Yap) Community Health Centers to improve accessibility and expand primary care services for low-income and vulnerable populations. Even these four CHCs are co-applicants with the State Department of Health Services and therefore all care is under the same authority. However, FSM EHDI will look into any other necessary partnerships to address gaps.

A plan for inclusion of all into the program regardless of race, ethnicity and geography will be drafted. The people of the FSM are highly diverse with nine main and different ethnic groups speaking some thirteen (13) different languages. The EHDI Program respects the cultural and linguistic diversity and seeks appropriately paired demographics within its staff, community leaders and families that participate in the program on each island state. In addition, EHDI Program staff are proficient in relaying health information in easy-to-understand vernacular. One identified service gap is among the birth of infants on the outer islands of FSM. As described above FSM consists of 607 islands separated by hundreds of miles of Pacific Ocean accessible only by airplane or boat, but only four islands offer health and hospital services including newborn hearing screening. Although not many births (approximately 200/year) occur on these outer islands, these births greatly affect the one (1) month screening data. With the addition of documenting location of birth in HER, the program can analyze and report this distinction allowing the FSM EHDI program to determine focused strategies for improvement on this disparate population.

The project will be monitored and evaluated as described in the work plan and Evaluation

section below. The program monitoring activities will occur annually and will track the extent to which the activities are implemented as designed and determine areas for improvement and to inform program development and service delivery. These project results will be disseminated to stakeholders during IAC state meetings as well as formally during the biennial Interagency Conference. These inter-agency forums are the best venue for broad dissemination because they include all partners including clinicians, partner organizations, consultants, families and community organizations. FSM will also make project results available to National and State level leadership.

Quality improvement (QI) will occur on a continuous basis as part of the evaluation process. A minimum of two areas for improvement will be addresses throughout the four year grant cycle based on identified needs from the annual evaluation described below in Evaluative Measures. QI teams have been established in each state consisting of the EHDI Coordinator, the EHDI Follow Up Coordinator, the EHDI Data Clerk, the MCH Coordinator, a parent representative and a physician. Together with the oversight of the evaluator, the team implements a data-driven, quality assessment and performance improvement process that looks at state-level aggregate data obtained from the HER data system. Data can be queried and analyzed at the state and National level as needed to meet the needs of the QI projects. The QI is a state-based process that will assess services offered through EHDI. As a state-based process it allows the four states to focus on individual areas of need to achieve greater overall program impact. It is an ongoing process to achieve measurable improvement in screening and outcomes and reduce loss to follow up by using indicators or performance measures associated with improved outcomes including early intervention and family engagement.

An additional activity is to provide education to lawmakers to increase the number of states with legislation mandating newborn hearing screening. Currently only two of the four states have this legislation. The mandate for screening will improve the program in two ways. One it will improve the percentage of newborns screened and it will require that local funding be allocated to the program to sustain the mandated screening efforts.

FSM intentionally does not plan to develop or promote a website for the exclusive use of D/HH families to receive information and resources. The NOFA outlines that such a website or webpage should be accessible and culturally appropriate for families, however that is a contradiction in the FSM. Internet access in FSM is poor and most do not have access outside of work and then only if they have an office-based job which are not many. Therefore, committing time and resources to a website or webpage that by its very nature is inaccessible and culturally inappropriate would be unsuitable and misguided. The FSM Division of Family Health is in the infancy stages of a website development for the small minority of the population that may desire it, <http://fsm2016mch.wixsite.com/fsmfamilyhealth>. This endeavor will be continued, promoted and evaluated to determine use and demand. Committing further resources to the website will be determined based on the findings.

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

The only objective for this goal is to increase the number of health professionals and service providers trained on key aspects of the EHDI Program. This will be accomplished through activities previously described under the first goal; to provide on-going technical assistance to screening staff and National EHDI Program related to screening and follow-up practices, provide

educational opportunities to staff through attendance to the National EHDI Conference (up to 2 staff annually), collaborate with regional and national programs for educational and training resources, EHDI staff will present on EHDI related content presentations to special education staff as needed, JOY Consulting staff will present at the biennial FSM Interagency Conference, and educate program partners on expanded hearing screening up to age three (3).

Health professionals' knowledge of the EHDI System will be achieved through professional development opportunities. FSM EHDI staff will provide the objective activities of presentations on EHDI related content to public health, hospital and CHC staff, EHDI related content to special education staff as needed.

The contract with JOY Consulting will provide presentations on EHDI related specialty content at the annual conference for health and special education. A compounding challenge to the remoteness of the FSM is the limited expertise in early intervention among education professional in the FSM. However, through training made available through HRSA-EHDI, both special education and health professionals can, not only been trained in early intervention for birth to three, but can benefit from the collaborative relationships that have been forged as a result of joint training.

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

The only objective for this goal is to increase family leadership within the FSM EHDI program and systems. This will be accomplished through recruiting additional families to serve on the EHDI Advisory Committee as needed, supporting the participation of parents of children who are d/hh and adults who are d/hh to contribute to FSM EHDI planning and activities with healthcare professionals and service providers, supporting parent attendance at state and national professional development conferences targeting family engagement (one parent annually), and identifying national organizations that provide family support (i.e. Hands and Voices through the Family Leadership Language and Learning grant).

Additional families will be recruited to serve on the EHDI Advisory Committee so that at least 25% of the committee is parents or family members of infants or children who are deaf or hard of hearing and/or deaf or hard of hearing individuals. Adults who are deaf or hard of hearing will be identified in each state. As described above, in the four states, an interagency agreement has been developed that involves the Children with Special Needs Program including EHDI Program, MCH Program, the State Hospital, the Department of Education, Special Education Program, the Early Childhood Education Program, and the Parent Network. This interagency agreement has been established to assure that children are screened for disabilities, and those who are suspected of having a disability are referred to the appropriate program for an assessment. The agreement also assures that an interdisciplinary team of members from each of the agencies is available to conduct an assessment, develop the individualized plan, and provide or coordinate the services. Each state has an Inter-Agency Council (IAC) consisting of representative from Public Health, Special Education, community groups such as churches, traditional leaders, NGOs and advocacy bodies, as well as parents and consumers of the CSHCN and EHDI services. A Maternal Child Health staff member represents the program on each of the state's Inter-Agency Council. Being that each state has an IAC the diversity of each state's population is represented appropriately. The FSM Department of Education, in particular the Early Intervention Service, is an essential partner of the EHDI Program. Together the agencies

offer services for children served by the FSM Department of Education and the Public Health Program for Children with Special Needs. Each state has established coordinated relationships and linkages among the local Departments of Education - Special Education, Population Education Projects, and Early Childhood Education Program and social services. With the establishment of these inter agency linkages, gaps in communication have narrowed and duplication of efforts has been minimized. However, the current use of the parent/program partnership is limited in the FSM. In Kosrae, the IAC meets monthly and has approximately twenty (20) members, half of which are parents and consumers. In Chuuk, the IAC has blended with the duplicative Special Education Board which had the same association objectives and focus. The Special Education Board meets quarterly and has approximately fifteen (15) members, half of which are parents or consumers. In Yap, the IAC is not very active and attempts to meet quarterly but with difficulty. Only one (1) parent serves on the council. In Pohnpei, the IAC has not met for at least two (2) years. Where the IAC is active, parents and consumers have an equal say and equal vote to other members in the business of the council. Council business centers around patient rights, program policies, access issues, and needs and gaps in services provided. The EHDI program intends to expand its parent/consumer partnership in the coming years to improve public input into the program and support the participation of parents of children who are deaf/ hard of hearing to contribute to FSM EHDI planning and activities. Adults who are deaf and hard of hearing will be identified and invited to participate in the EHDI Advisory Committee as well.

Because the following programs do not exist within the FSM, they are not included in the EHDI Advisory Committee: Title XIX - Medicaid, Title XXI - Child Health Insurance Program, Part C IDEA, HOME Visiting, Child Welfare Programs, Social Security Administration, WIC Program, Rehabilitation Services, Newborn Bloodspot Screening, Family-to-Family Health Information Centers, Schools or Offices for the Deaf, State Chapters of the American Academy of Pediatrics or equivalent, Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs or on-island Family Organizations.

In addition, FSM EHDI will support parent participation in the EHDI learning communities and at the Interagency Conference and support parent attendance at state and national professional development conferences targeting family leadership development.

FSM will also identify national organizations that assist in providing family support. For example, FSM EHDI will work with the Family Leadership Language and Learning grant (FL3 Center) and continue its established partnership with Hands and Voices established this past grant cycle.

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

The only objective for this goal is infants identified as d/hh will be enrolled in deafness specific early intervention services focused on early parent-child relationship development and language acquisition. This will be accomplished through assessing the capacity of coordination across programs, building the capacity of coordination amongst the program staff, families and SpEd staff through a teaming model by providing family/service provider education classes, providing hearing aids so that a child diagnosed with a hearing loss that would benefit from amplification, might be fit within three months of diagnosis to improve effective intervention, and providing language acquisition services from a licensed speech language pathologist with a background

and expertise in deafness.

The coordination of all program services in the FSM will be evaluated, so that any time a child is identified with any hearing loss, JOY Consulting and SpEd are notified. Based on the findings, in year two, FSM will make any improvements to improve this coordinated effort. This will prevent time delays due to lack of communication.

To increase the number of staff program staff, families and SpEd staff aware of, knowledgeable of and confident in providing EI services focused on early parent-child relationship development and language acquisition, FSM will provide family/ service provider education classes through a teaming model.

FSM will create a hearing aid bank. This will allow a child diagnosed with a hearing loss that would benefit from amplification, might be fit within three months of diagnosis so that intervention could be effective and language acquisition can be obtained.

Through its partnership with JOY Consulting, FSM EHDI will provide language acquisition services from a licensed speech language pathologist with a background and expertise in deafness.

Sustainability

The budget associated with the above methodologies can be found in the work plan and the budget justification. Funding and sustainability is a great concern for FSM. FSM relies upon Compact funding which is currently being reduced, therefore increasing its dependence on Federal grant opportunities. FSM is seeking additional opportunities beyond the HRSA EHDI funding to sustain the project. In addition, the inclusion of legislation that mandates newborn hearing screening in each state, as discussed above, will force local allocations to this endeavor beyond Federal funding focusing on key elements of the projects, such as strategies or services and interventions which have been effective in implementing EHDI system reform by improving infrastructure support mechanisms and those that have led to improved outcomes for deaf and hard of hearing children.

▪ *WORK PLAN*

Please see Attachment 1 Work Plan and Logic Model.

The work plan focuses the program activities towards four goals; 1) Ensure that infants receive appropriate timely services, including screening, evaluation, diagnosis, and early intervention by leading efforts to engage and coordinate all stakeholders of the EHDI System; 2) Engage, educate, and train health professionals and service providers in the EHDI system; 3) Strengthen capacity to provide family support and engage families with children who are D/HH as well adults who are D/HH throughout the EHDI system; and 4) Facilitate improved coordination of care and services for families and children who are D/HH.

The activities include supporting infrastructure that ensures 1-3-6 recommendations; reduces loss to follow up and loss to documentation; supports hearing screening, data collection and reporting for children up to age three (3); partners with other stakeholders such as Title V Maternal Child Health and Children with Special Health Care Needs; and collaborates with federal EHDI partners. Accommodations are made for the lack of certain services and federal programs in the FSM. Off-island audiologists will be contracted for teleaudiology for two of the states and on-

site visits for the other two. An off-island speech and language therapist will be contracted for language development support.

Additional activities support stakeholder involvement through an advisory committee; outreach and education to health professionals and service providers about the EHDI recommendations; and family engagement throughout all aspects of the program including partnering with professionals and healthcare providers. Program evaluation activities include quality improvement, assessment of coordinated care including communication, training, referrals and data sharing. An independent evaluator is contracted to assess, monitor and track progress towards program objectives.

▪ *RESOLUTION OF CHALLENGES*

The most likely challenges that the program anticipates is related to the remote location of the island and limited access to specialists and specialty supplies. To combat that challenge the program relies on its small size and close association with complementary services. This allows the EHDI Program to adapt and alter its plans as necessary to accommodate and resolve challenges as the program is implemented.

FSM's EHDI Program has a solid working collaboration with the public and private sectors as well as governmental and non-governmental organizations. Because of the small size of FSM and the limited healthcare services, the medical home concept is very different in this region. Health services in the FSM are designed and delivered at the State level. The State is responsible for all medical and health services in the state. Each state has a central State Hospital with medical, nursing, and support personnel that provide all of the acute inpatient and outpatient medical services for the residents of the state. With limited facilities and even more limited staff, there are not multiple unrelated facilities where patients receive services. FSM Maternal Child Health Title V programs, other HRSA programs, other programs within the Division of Public Health, other governmental agencies, and other local public and private organizations are involved throughout EHDI project planning and implementation, as are a wide array of stakeholders and family members.

The FSM Department of Education, in particular the Early Intervention Service and Special Education, is an essential partner of the EHDI Program. Title V Children with Special Health Care Needs Program (CSHCN) is also an integral partner to EHDI. Together the agencies offer services for children served by the FSM Department of Education and the Public Health Program for Children with Special Needs. In the four states, an interagency agreement for the CSHCN Program has been developed that involves the CSHCN Program, MCH Program, the State Hospital, the Department of Education, Special Education Program, the Early Childhood Education Program, and the Parent Network. This interagency agreement has been established to assure that children are screened for disabilities, and those who are suspected of having a disability are referred to the CSHCN Program for an assessment. The agreement also assures that an interdisciplinary team of members from each of the agencies is available to conduct an assessment, develop the individualized plan, and provide or coordinate the services. Each state has established coordinated relationships and linkages among the local Departments of Education - Special Education, Population Education Projects, and Early Childhood Education Program; and social services. With the establishment of these inter agency linkages, gaps in communication have narrowed and duplication of efforts has been minimized.

The lack of on-island specialists is combatted by the program partnering with audiologists and other professionals for support and services. Two audiologists are currently on contract- one to provide teleaudiology for Pohnpei and Chuuk from Wisconsin and one to provide on-site DAE in Yap and Kosrae more regionally from Guam. Dr. Angie Mister, Audiologist in CNMI, is the National Center for Hearing Assessment and Management (NCHAM) contact for FSM and assists with quality improvement projects and measures. All three audiologists also assist with resolving any program challenges in designing and implementing work plan activities. Dr. Clare Camacho, a licensed speech and language therapist from JOY Consulting in Guam, is currently on contract and will continue to be contracted to provide the intervention and family support required by this announcement which is not available on-island.

▪ *EVALUATION AND TECHNICAL SUPPORT CAPACITY*

The program evaluation will monitor ongoing processes and the progress towards the goals and objectives of the project as identified in the work plan. The evaluation will be conducted through a contract to provide an independent assessment of the program. The contractor, AB Consulting, has been with the program since 2015 and therefore knowledgeable to the programs goals and objectives, as well as staff, services, data and resources.

The evaluation plan is to measure the impact of the project as well as monitor the efficiency of the proposed project activities. Overall the evaluation will assess if the program identifies newborn and infant screening and if those newborns and infants identified as deaf/ hard of hearing receive timely evaluation, diagnosis and intervention that optimize language, literacy and social-emotional development.

Looking individually at the funding objectives, the following measurements will be utilized.

Increase the number of newborns that receive timely diagnosis in accordance with 1-3-6.

Target 1 = improve the screening rate to 89% or more screened by 1 month

Target 2= improve the diagnostic audiological evaluation rate by 3 months to 85% or more

Target 3= maintain the early intervention rate by 6 months at least 80%

Increase the number of families receiving support services.

Target 1= Increase by 20% from year one baseline the number of families enrolled in family-to-family support services by no later than 6 months of age.

Target 2= Increase by 10% from year one baseline the number of families enrolled in D/HH adult-to-family support services by no later than 9 months of age.

Increase the number of health professionals and service providers trained on key aspects of the EHDI Program.

Target 1= Increase by 10% from year one baseline the number of health professionals and service providers trained on key aspects of the EHDI Program.

In addition to the ability to meet the 1-3-6 recommendations and provider outreach and education, the evaluator will the following program components:

- Loss to follow up/documentation
- Expansion of screening up to age 3
- Data collection
- Telehealth
- Outreach to underserved populations
- Late onset hearing loss
- Partnerships across Title V and other early childhood programs
- Family engagement and family support

Data for the above 1-3-6 measures including loss to follow up or documentation is currently being and will continued to be collected, tracked and analyzed using the FSM EHDI-IS HER system. The HER data system collects all newborn hearing data on an individual basis, no aggregated data sources are used. All data- screened or not screened, inpatient or outpatient, initial or rescreen, and passed or not passed- are 100% individually reported in the HER system. For all infants that are not screened, or did not pass newborn hearing screening the EHDI-IS, HER, system is able to gather individual level information on infants that do not pass the hearing screening and on infants who have no documentation of hearing screen being performed. The HER system is maintained by the State EHDI Data Clerks that have been trained by the system developer. Data should be entered on the day of screening or service which allows for accurate and timely reporting of performance outcomes. Data is managed and analyzed by either the National MCH Data Manager or the contracted Evaluator. Both are skilled in data analysis with more than ten years of experience each.

One potential barrier to the evaluation plan is timeliness of data entry. Incremental improvements have been made to improve the user experience of HER, including training with a focus on quality improvement, permitting aggregated national reporting by state, reinforcement of program protocols for data entry, and training on new features. The aggregated reporting by State created a new national level report that provides aggregate data across all four State programs, broken down by state allowing a greater understanding of areas of program need and improvement. There are several new technologies and approaches that can be leveraged to make all of the pages load and save faster. In addition to improving the user experience in general, this initiative can help with the quality of data entry because it will allow for data entry in real-time. Instead of waiting until after hours, the screening data is now being entered during the day, even when the FSM networks are typically saturated with use. In this scenario, the FSM HER dashboard has become more used and valuable. For example, the inpatient queue on the dashboard tells the screener who needs to be screened today. With more timely birth and screening data entry, the dashboard will be used more to help staff manage their day, and coordinators and the evaluator to monitor the strength of their program.

Data for the above support services and training measures will be collected by the contracted Evaluator through additional quantitative and qualitative strategies to allow for accurate and timely reporting. Baseline will be determined during year one and reported on in progress reports.

Quality improvement (QI) will occur on a continuous basis as part of the evaluation process. A

minimum of two areas for improvement will be addresses throughout the four year grant cycle based on identified needs. QI teams have been established in each state consisting of the EHDI Coordinator, the EHDI Follow Up Coordinator, the EHDI Data Clerk, the MCH Coordinator, a parent representative and a physician. Together with the oversight of the audiologist, the team implements a data-driven, quality assessment and performance improvement process that looks at state-level aggregate data obtained from the HER data system. Data can be queried and analyzed at the state and National level as needed to meet the needs of the QI projects. The QI is a state-based process that will assess services offered through EHDI. As a state-based process it allows the four states to focus on individual areas of need to achieve greater overall program impact. It is an ongoing process to achieve measurable improvement in screening and outcomes and reduce loss to follow up by using indicators or performance measures associated with improved outcomes including early intervention and family engagement.

The program monitoring activities will be updated at least annually and will track the extent to which the activities are implemented as designed and determine areas for improvement and to inform program development and service delivery. These project results will be disseminated to stakeholders during state meetings as well as formally during the annual FSM EHDI Conference and the Interagency Advisory Council Conferences. These inter-agency forums are the best venue for broad dissemination because they include all partners including clinicians, partner organizations, consultants, families and community organizations. FSM will also make project results available to National and State level leadership.

- *ORGANIZATIONAL INFORMATION*

There are two levels of government in the FSM, the National Government level and the State Government level. The FSM is self-governing with locally elected President, Vice President and Congress at the National level. Each State also elects a Governor, Lieutenant Governor, and Legislature. For the purposes of receiving U. S. Federal Domestic Assistance, the National Government is designated as the "State Agency". However, all funds approved by the U. S. Federal Government to support EHDI and allocated to the FSM Government are further allotted to each State EHDI Program by way of Allotment Advices issued by the National Budget Office.

At the National level, the Secretary of the Department of Health and Social Affairs (H&SA) manages health affairs for the nation. There are two divisions under H&SA, including the Division of Health Services which houses the Family Health Services Section. The Maternal and Child Health Program is one of the six programs under the Family Health Services Section along with Title X Family Planning, UNFPA Family Health Project, HRSA and CDC funded Early Hearing Detection and Intervention (EHDI) Programs, and State System Development Initiative (SSDI). The Program Manager of the Family Health Services Section also acts as the National EHDI Program Coordinator. Please see Attachment 2: Staffing Plan and Job Descriptions of Personnel, Attachment 3: Biographical Sketches of Key Personnel and Attachment 5: Organizational Chart.

Because all of the islands' healthcare, including inpatient and outpatient care at the primary, secondary and tertiary care levels, is administered through the Department of Health and Social Affairs as a single authority system, physician engagement across the healthcare system is effortless. All healthcare providers work within the system and therefore aware of the EHDI program and its offerings. Further engaging primary care providers into the program as outlined

in this application should not be difficult.

FSM's EHDI Program has a solid working collaboration with the public and private sectors as well as governmental and non-governmental organizations. FSM Maternal Child Health Title V programs, other HRSA programs, other programs within the Division of Public Health, other governmental agencies, and other local public and private organizations are involved throughout project planning and implementation, as are a wide array of stakeholders and family members.

The FSM Department of Education, in particular the Early Intervention Service and Special Education, is an essential partner of the EHDI Program. Title V Children with Special Health Care Needs Program is also an integral partner to EHDI. Together the agencies offer services for children served by the FSM Department of Education and the Public Health Program for Children with Special Needs. See Attachment 4: Letters of Agreement.

As described previously in this application each state has an Inter-Agency Council (IAC) consisting of representative from Public Health, Special Education, community groups such as churches, traditional leaders, NGOs and advocacy bodies, as well as parents and consumers of the CSHCN and EHDI services. It is through this established collaboration that the EHDI program will further engage families of the deaf/hard of hearing community. Given the small size of FSM, these individuals and families are well known to the program, making engagement easier than in other locations. It is also through the close involvement with the IAC that the unique needs of target population of the communities served are routinely assessed and improved. Community needs are formally assessed at the National IAC Conference and informally assessed at the state level throughout the year.

The FSM EHDI program is fully staffed at the National and State levels. At the National level Dionis Saimon serves as EHDI Coordinator, and is responsible for the organization to follow the approved plan outlined in this application. Additionally, Vicky Nimea serves at the National level to properly account for the federal funds and document all costs to avoid audit findings. At the State level, each state has an EHDI Coordinator, a Follow-up Coordinator and an EHDI Data Clerk experienced in tracking and monitoring EHDI surveillance activities. Please see Attachment 5: Organizational Chart.

Elizabeth Seeliger, Audiologist from Global Impact Audiology in Wisconsin, is currently on contract to provide teleaudiology for Pohnpei and Chuuk to improve DAE. Renee Koffend, Audiologist from Guam Hearing Doctors in Guam, is currently on contract to provide on-site DAE in Yap and Kosrae. These contracts have led to the noted successes with DAE and will therefore be continued during this next cycle. In addition, Angie Mister, Audiologist in CNMI, is the National Center for Hearing Assessment and Management (NCHAM) contact for FSM and assists with quality improvement projects and measures.

Dr. Clare Camacho, a licensed Speech and Language Pathologist of JOY Consulting in Guam, is currently on contract to facilitate partnerships with and engage families, health professionals, and service providers in the early intervention activities of those identified as D/HH. This contract has been shown to be valuable and effective and will therefore be continued.

Arielle Buyum has been contracted to provide evaluation services for the FSM EHDI Program since 2015. Ms. Buyum, MPH, CPH, is the principal owner of AB Consulting, LLC in CNMI. She holds a Master Degree in Public Health from the Rollins School of Public Health at Emory University and a Bachelor of Science in Nursing. Her expertise in healthcare spans two decades

of practical delivery of care and public health development. Her experiences include providing technical assistance services for the Pacific Islands Primary Care Association including quality improvement plans and efforts. Ms. Buyum's professional experience in multiple healthcare system settings provides a robust and multifaceted vision on regional healthcare. The evaluation findings have influenced program direction and decision-making which has resulting in the improvements described in this application.

Quality Improvement teams have been established in each state consisting of the EHDI Coordinator, the EHDI Follow Up Coordinator, the EHDI Data Clerk, the MCH Coordinator, a parent representative and a physician. Together with the oversight of the evaluator, the team implements a data-driven, quality assessment and performance improvement process that looks at state-level aggregate data. It is a state-based process that will assess services offered through EHDI. As a state-based process it allows the four states to focus on individual areas of need to achieve greater overall program impact. It is an ongoing process to achieve measurable improvement in screening and outcomes and reduce loss to follow up by using indicators or performance measures associated with improved outcomes.