Mom holding baby boy.

# Guam Early Hearing Detection & Intervention Project (Guam EHDI) Annual Report

Project Period: July 1, 2018 - June 30, 2019

# About Guam EHDI

The Guam EHDI Project was established in 2002 through a federal grant awarded to the

University of Guam Center for Excellence in Developmental Disabilities Education, Research,

& Service (Guam CEDDERS). The Guam EHDI Project receives support through a grant from

the U.S. Health and Human Services (HHS), Health Resources and Services Administration

(HRSA). The Centers for Disease Control and Prevention (CDC) also provides funding support

to complement Universal Newborn Hearing Screening on Guam by implementing Guam

ChildLink-EHDI, an integrated data tracking & surveillance system to support the Guam EHDI

Project.

Through the efforts of this Project, the Universal Newborn Hearing Screening and

Intervention Act, Public Law 27-150, became law in December 2004. Guam’s local legislation

aligns with national goals and ensures a standard of care for all babies born on Guam.

The Guam EHDI Project promotes the following Joint Commission on Infant Hearing (JCIH)

guidelines (known as the “1-3-6 Plan"):

* all babies born on Guam are screened for hearing loss by 1 month of age;
* babies with hearing loss are diagnosed by 3 months of age;
* quality early intervention services they need are initiated by 6 months of age.

Early identification of hearing loss is important because:

* Hearing loss is the most frequent birth defect. \*
* Undetected hearing loss has serious negative consequences.
* There are dramatic benefits associated with early identification of hearing loss.

\*Source: National Center on Hearing Assessment & Management (NCHAM), Utah State University.

Picture showing *March 1, 2019: Marie Wusstig, CEDDERS Training Associate, and JJ Mendiola, Interoperability Data Manager, highlighted the two major accomplishments the Guam Early Hearing Detection & Intervention (EHDI) Project achieved in 2018 during the Islands/Outlying Territories Meeting at the 2019 EHDI Conference held in Chicago, IL. Not pictured: Jenika Ballesta, CEDDERS Research Associate. These accomplishments included attaining a significant improvement in the completion rate for Diagnostic Audiological Evaluations (DAE) in 2018 and the establishment of an active parent mentoring and leadership partnership*.

# Types of Hearing Loss Identified from November 2002-March 2018

A listing of the number of types of hearing loss: 58 Conductive, 29 Sensorineural, 7 Mixed, 9 Undetermined which equals to an overall of 103 in total.

1Conductive Hearing Loss - Type of hearing loss where sound is not conductedefficiently through the outer ear canal to the eardrum and can often be medically or surgically corrected.

2Sensorineural Hearing Loss - Type of hearing loss when there is damage to the inner ear or to the nerve pathways from the inner ear to the brain.

3Mixed Hearing Loss - Type of hearing loss that is a combination of conductive

hearing loss and sensorineural hearing loss.

Note: Data is from infants born at civilian sites: Guam Memorial Hospital Authority (GMHA), Sagua Mañagu Birthing Center (SMBC), and Guam Regional Medical City (GRMC).

There were 103 infants identified with a hearing loss since the Guam EHDI project began in 2002. These infants were all offered early intervention services through the Guam Department of Education, Guam Early Intervention System.

# Initial Screening\*

\* Initial Screening - Screening of infants for potential hearing loss prior to discharge from the birthing site by calendar year.

A graph portraying the percentage and the benchmark for the initial screening from 2015 to 2018. In 2015, 99% were screened with 99% benchmarked. In 2016, 99% were screened with 99% benchmarked. In 2017, 99% were screened with 99% benchmarked. Finally, in 2018, 99% were screened with 99% benchmarked.

The Guam EHDI project has maintained a 99% initial hearing screening rate at all civilian birthing sites.

# Percent Lost to Follow Up at Outpatient Rescreen\*

\*Outpatient rescreen - Follow-up rescreen of infants who did not pass their initial hearing screening.

A graph portraying the percentage and the benchmark for Lost to Follow Up (LFU) outpatient rescreen from 2015 to 2018. In 2015, 1.8% were lost to follow up outpatient rescreen with 10% benchmarked. In 2016, 5.3% lost to follow outpatient rescreen with 10 % benchmarked. In 2017, 8.8% lost to follow up outpatient rescreen with 10% benchmarked. And in 2018, 7.3% lost to follow up outpatient rescreen with 10% benchmarked.

The Lost to Follow Up (LFU) rate for outpatient rescreens was at 1.8% in 2015. In 2016, the rate for outpatient rescreen increased to 5.3% and increased to 8.8% in 2017. In 2018, the rate decreased to 7.3%. The LFU rate remained below the 10% benchmark level during this four year period.

# Percent Lost to Follow Up at High Risk Rescreen\*

\* High Risk Rescreen - Follow-up rescreen of infants who passed their initial hearing screening but have risk factors for potential late onset hearing loss.

The Lost to Follow Up\* (LFU) rate for High Risk Rescreens was at 11.2% in 2015. In 2016, the rate 30 decreased slightly to 11.1%. In 2017, the rate increased to 17.9%, then more than doubled in 2018 to 38.3%. The rate exceeded the benchmark of 10% for all four years.

*\* Lost to Follow-up (LFU) is defined as*

1. *Cannot be located – incomplete or inaccurate address,*
2. *Cannot be contacted – no working phone number, wrong number*
3. *Unresponsive – made initial contact with family, 3 attempts made to reconnect, no response from the family.*

A graph portraying the percentage and the benchmark for Lost to Follow Up for High Risk Rescreen from 2015 to 2018. In 2015, 11.2% lost to follow up for high risk rescreen with 10% benchmarked. In 2016, 11.1% lost to follow up for high risk rescreen with 10% benchmarked. In 2017, 17.9% lost to follow high risk rescreen with 10% benchmarked. And in 2018, 38.3% lost to follow up high risk rescreen with 10% benchmarked.

# Diagnostic Audiological Evaluation (DAE)\*

\*Infants who do not pass a follow-up rescreen, receive a DAE to determine whether or not a hearing loss is present and if so, the type and severity of the hearing loss.

A chart showing the number of Total’s for the Diagnostic Audiological Evaluation from 2015 to 2018. In 2015: 55 were referred for a diagnostic evaluation, 26 completed their diagnostic evaluation, 4 with diagnostic evaluation by 3 months, 21 with normal hearing, 5 with hearing loss, 0 undetermined, 3 receiving Early Intervention services, 1 receiving early intervention services before 6 months, 8 were pending diagnostics, 0 deceased, 19 relocated or refused services and 2 lost to follow up.

2016: 53 referred for diagnostic evaluation, 18 completed diagnostic evaluation, 5 with diagnostics evaluation by 3 months, 11 with normal hearing, 6 with hearing loss, 1 undetermined, 1 received early intervention services, 1 received early intervention services before 6 months, 4 pending diagnostics, 0 deceased, 13 either relocated or refused services and 18 lost to follow up.

2017: 33 referred for diagnostic evaluation, 17 completed diagnostic evaluation, 6 with diagnostic evaluation by 3 months, 7 with normal hearing, 9 with hearing loss, 1 undetermined, 5 received early intervention services, 2 received early intervention services before 6 months, 1 pending diagnostic evaluations, 0 deceased, 6 either relocated or refused services and 9 lost to follow up.

2018: 25 referred for diagnostic evaluation, 19 diagnostics evaluation completed, 13 with diagnostic evaluation by 3 months, 14 with normal hearing, 4 with hearing loss, 1 undetermined, 0 received early intervention services, 0 receiving early intervention before 6 months, 2 pending diagnostics evaluation, 0 deceased, 1 either relocated or refused services and 3 lost to follow up.

There were a total of 32 infants Lost to Follow Up (LFU) between 2015-2018. Guam EHDI continues to focus efforts on decreasing LFU for infants needing diagnostic audiological evaluation. Guam EHDI’s audiologist consultant and Guam Early Intervention staff continue to assist the project with quality improvement activities to address this.

*December 30, 2018: Guam’s Positive Parents Together, Inc. (GPPT)/Project Fitme held their 2nd Family Social Event at the Onward Beach Resort Guam Water Park. The purpose of the Family Social Events is to promote social interaction between families who have young children with hearing loss and who are involved with the D/HH Family Support Group. Pictured front row from left to right: Evelyn Topasna; Gatbo Topasna; Caleb Suzuki; Liam Cruz. Back row: Susan Dugan (GPPT Staff); Ashley Babauta (GPPT Staff); Nathan Manibusan (ASL Community Interpreter) and Ivan Babauta (ASL Community Interpreter); Trisha Suzuki; Jay-Lynn Mendiola and John Mabayag.*

# Project Achievements

* Benchmarks (targeted numbers) were met for hearing screening performed on newborns at the civilian birthing sites before 1 month of age and infants needing outpatient rescreen.
* Strategies used to reduce the number of infants lost to follow-up in the outpatient rescreen category included:
	1. Scheduling and giving hearing screening outpatient appointments from the birthing sites before discharge;
	2. Offering flexible hearing screening appointment dates and sites; and
	3. Making reminder calls about appointment date and time.
* Public awareness on the importance of early detection of hearing loss through the screening and evaluation processes was greatly enhanced by the Project’s participation in 21 community outreach activities.
* Guam EHDI and the University of Hawaii, Telecommunications and Social Informatics (TASI) Research Program, continued to collaborate on the efforts toward interoperability between the Electronic Health Record (EHR) at the Department of Public Health and Social Services (DPHSS) and Guam ChildLink - EHDI.
* Efforts continued to strengthen the data collection and reporting system in preparation of the long- term goal of turning ChildLink - EHDI over to system partners.
* DPHSS, in collaboration with Guam EHDI, provide monthly hearing screening for infants identified with high-risk factors for hearing loss at the DPHSS Central Health Clinic. Infants screened having Medicaid/MIP medical insurance receive a same day referral to the audiologist should they refer
on the hearing screening at this level of care. This additional improvement to the system not only speeds up the time for an evaluation by an Audiologist, but also is a step towards sustainability and strengthening our system of services.
* More personnel received training and are inputting data into ChildLink EHDI which also strengthens tracking and surveillance efforts.
* A Memorandum of Agreement was finalized and executed with Guam's Positive Parents Together, Inc. (GPPT), a local nonprofit organization to implement the parent engagement component of Guam EHDI-Fitme. Three parent mentors signed commitment letters to provide support to families of children who are deaf/hard of hearing (d/hh). A parent support group was established for families of children identified with a hearing loss. Three family activities occured which helped the group establish relationships to support one another.
* The Guam EHDI Learning Community, adopted a paper form “Shared Plan of Care” (SPoC) to be housed by GPPT. This SPoC includes medical and educational information for children identified with a hearing loss which parents can share with professionals who care for their child.

Guam Early Hearing Detection Intervention (EHDI) logo

University of Guam (UOG) logo

Guam CEDDERS logo

For more information, visit [www.guamehdi.org](http://www.guamehdi.org) Guam EHDI

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Group picture taken on *February 20, 2019: Guam Early Hearing Detection & Intervention (EHDI) Project, Guam Positive Parents Together, and Guam Department of Education – Guam Early Intervention System met with North Carolina Early Hearing Detection & Intervention (EHDI) staff. Both EHDI Teams were able to share their experiences and the resources within their programs with one another. Front row left to right: Jenika Ballesta, Guam CEDDERS, Research Associate, Marie Wusstig, Guam EHDI, Training Associate; Beth Whitfield, NC Early Learning Sensory Support Program; Tisha Suzuki, Parent Mentor; Susan Dugan, GPPT Project Fitme Coordinator; Cathy Tydingco, GDOE-GEIS, School Program Coordinator; Ann Marie Cruz, GPPT Board President; Johnnie Sexton, CARE Project, Founder, Executive Director; NC-EHDI staffs; Evelyn Topasna, Parent Mentor; Tanya Simer, Guam EHDI, Hearing Screening Paraprofessional.*

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