Mom holding baby girl while getting a Hearing Screening from Hearing Screening Facilitator.

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

Project Period: July 1, 2017 - June 30, 2018

# 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 Guam EHDI Advisory Committee and Learning Community Meeting, March 6, 2018.

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

A listing of the number of types of hearing loss: 58 Conductive, 28 Sensorineural, 7 Mixed, 6 Undetermined which equals to an overall of 99 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 99 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 2014 to 2017. In 2014, 99% were screened with 98% benchmarked. In 2015, 99% were screened with 99% benchmarked. In 2016, 99% were screened with 99% benchmarked. Finally, in 2017, 99% were screened with 99% benchmarked.

The Guam EHDI project has maintained a 99% initial hearing screening rate at all civilian birthing sites. Guam Regional Medical City data is included in the 2015 to 2017 screening rate.

# 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 2014 to 2018. In 2014, 5% were lost to follow up outpatient rescreen with 10% benchmarked. In 2015, 2% lost to follow outpatient rescreen with 10 % benchmarked. In 2016, 3% lost to follow up outpatient rescreen with 10% benchmarked. And in 2017, 8% lost to follow up outpatient rescreen with 10% benchmarked.

The Lost to Follow Up (LFU) rate for outpatient rescreens decreased to 2% in 2015. The LFU rate slightly increased to 3% in 2016 but remained below the benchmark for this level. The LFU rate

slightly increased to 8% in 2017, but remained below the benchmark for this level for 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 17% in 2014, which is below the

benchmark for that year. In 2015, the rate decreased to 16%, but was 6% over the established 10%

benchmark for the year. In 2016, the rate significantly decreased to 10%, meeting the established Guam EHDI benchmark. In 2017, the rate increased to 15% exceeding the benchmark for that year.

A graph portraying the percentage and the benchmark for Lost to Follow Up for High Risk Rescreen from 2014 to 2017. In 2014, 17% lost to follow up for high risk rescreen with 20% benchmarked. In 2015, 16% lost to follow up for high risk rescreen with 10% benchmarked. In 2016, 10% lost to follow high risk rescreen with 10% benchmarked. And in 2017, 15% 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 2014 to 2017. In 2014: 53 were referred for a diagnostic evaluation, 29 completed their diagnostic evaluation, 13 with diagnostic evaluation by 3 months, 20 with normal hearing, 8 with hearing loss, 5 receiving Early Intervention services, 4 receiving early intervention services before 6 months, 6 were pending diagnostics, 1 deceased, 12 relocated or refused services and 5 lost to follow up.

2015: 53 referred for diagnostic evaluation, 26 completed diagnostic evaluation, 4 with diagnostics evaluation by 3 months, 21 with normal hearing, 5 with hearing loss, 3 received early intervention services, 1 received early intervention services before 6 months, 6 pending diagnostics, 0 deceased, 18 either relocated or refused services and 3 lost to follow up.

2016: 53 referred for diagnostic evaluation, 15 completed diagnostic evaluation, 6 with diagnostic evaluation by 3 months, 11 with normal hearing, 4 with hearing loss, 1 received early intervention services, 1 received early intervention services before 6 months, 10 pending diagnostic evaluations, 0 deceased, 13 either relocated or refused services.

2017: 32 referred for diagnostic evaluation, 12 diagnostics evaluation completed, 5 with diagnostic evaluation by 3 months, 5 with normal hearing, 5 with hearing loss, 3 received early intervention services, 1 receiving early intervention before 6 months, 15 pending diagnostics evaluation, 0 deceased, 2 either relocated or refused services and 3 lost to follow up.

There were a total of 26 infants Lost to Follow Up (LFU) between 2014-2017. Guam EHDI continues to focus efforts on decreasing LFU for infants needing diagnostic audiological evaluation. Guam EHDI’s audiologist consultant is assisting the project with quality improvement activities to address this.

The first meeting of the Deaf/Hard of Hearing Parent Support Group is shown on March 14, 2018. The purpose of the group is to establish a parent to parent support system to help parents of newly identified infants and toddlers with hearing loss learn about options and navigating systems. The meeting was facilitated through a partnership with Guam Positive Parents Together (GPPT), headed by Ann Marie Cruz, President, and the Guam Early Hearing Detection and Intervention (Guam EHDI) Project Fitme, administered by Guam CEDDERS. Parent support efforts are facilitated by Susan Dugan, BSW, Project Coordinator. Attending the meeting were (L-R) Tricia Suzuki, Joe Tuquero, Caleb Suzuki, Susan Dugan, Ann Marie Cruz, and Evelyn Topasna. Not Shown: Terrie Fejarang.

# Project Achievements

* Benchmarks (targeted numbers) were met for hearing screening performed on newborns at the civilian birthing sites before 1 month of age, infants needing outpatient rescreen, and infants needing a high risk 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 18 community outreach activities and website re-design and updates.
* 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.
* The High Risk Re-screening Clinic was moved to the Department of Public Health & Social Services Central Health Clinic. This was also a step towards strengthening our system of services and sustainability.
* More users received training and are inputting data into ChildLink EHDI which also strengthens tracking and surveillance efforts.
* Memoranda of Agreement were finalized and executed with two local nonprofit organizations to implement the parent engagement component of Guam EHDI-Fitme.
* Guam's Positive Parents Together (GPPT), Project Fitme Project Coordinator held parent meetings to recruit and provide introductory parent mentor training and established a partnership with GEIS to provide support to parents of children identified with a hearing loss.
* The Guam EHDI Learning Community, consisting of parents of children who are deaf and/or hard of hearing (D/HH), pediatricians, audiologist, the Guam Early Intervention System Project Coordinator, Department of Education D/HH Coordinator, Nurses, Birthing Assistants and Nursing Supervisors, a Medical Facility Manager, and the Department of Public Health and Social Services Bureau of Family Health & Nursing Services Administrator, was established to increase health professionals’ engagement and knowledge of the EHDI system.

On March 20, 2018, Guam Early Hearing Detection and Intervention (Guam EHDI) Project Fitme is shown receiving the 2018 Website of the Year Award at the Annual National EHDI Meeting held in Denver, Colorado. Karl White, Ph.D., Director of the National Center for Hearing Assessment and Management (NCHAM), commented on the improvements and accessibility of the site. The website was designed and constructed by Sherry Guerrero, former Disability Media Specialist, with content written and organized by the Guam EHDI Team. Accepting the award on behalf of Guam EHDI were (Front Row, L-R): Joseph Mendiola and Marie Wusstig. (Back Row, L-R): Karl White and Tony Ronco, parent with Hands and Voices.

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 March 29, 2018, of Joseph Mendiola, Interoperability Data Manager, who facilitated a Workgroup Evaluation Meeting with Guam Childlink-EHDI stakeholders and data system users. Mr. Mendiola, who also serves as the Guam EHDI Quality Improvement and Evaluation Coordinator, gave an overview on the progress Guam EHDI has made over the past year. Stakeholders were also asked to provide input to improve the quality of the data collected and ways to improve the EHDI services on all levels of the hearing continuum. Pictured (Left to Right – Renee Koffend AuD., Audiologist; Marie Wusstig, GEHDI Coordinator; Pamela Sablan, Guam Regional Medical City (GRMC); Brittney Babauta, GRMC; Cid Mostaies, Department of Public Health and Social Services (DPHSS); Barbara Leon Guerrero, Guam Early Intervention System (GEIS); Margarita Gay, Administrator, DPHSS Bureau of Family Health & Nursing Services; and Mr. Mendiola. Not shown: Terrie Fejarang, Guam EHDI Project Director; Mary Kidd, Guam EHDI Consultant; Ruth Leon Guerrero, Guam EHDI Office Technician; and Jenika Ballesta, Guam EHDI Hearing Screening Facilitator.

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