# 2017-2018

# Guam Early Hearing Detection & Intervention

# (Guam EHDI)

# Progress Report At-A-Glance

A picture of Trisha Suzuki and Son, Caleb on the cover.

A picture of Guam Early Hearing Detection and Intervention Logo.

A picture of University of Guam Logo and Guam CEDDERS.

# 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 grant was awarded by the U.S. Health

and Human Services (HSS), Health Resources and Services Administration (HRSA) to

support Guam’s Universal Newborn Hearing Screening Program. Guam EHDI also

receives support through a Cooperative Agreement by the U.S. HSS, Centers for

Disease Control and Prevention (CDC) to complement Universal Hearing Screening

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, was enacted in December 2004. Guam’s local

legislation aligns with national goals and assures an upgraded standard of care for all

babies born on Guam.

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

(JCIH) guidelines:

• 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

(known as the “1-3-6 Plan”).

# A chart showing the 2015-2017 Hearing Screening, Diagnosis, & Intervention Data

January through December 2015's Total births is 3373, total infant screened is 2942\*, total of infants diagnosed with hearing loss is 5, total of infants receiving early intervention services (EIS) is 3, and not receiving early intervention services is 21.

January through December 2016's Total births is 3440, total infant screened is 2984\*, total of infants diagnosed with hearing loss is 4, total of infants receiving early intervention services (EIS) is 1, and not receiving early intervention services is 32.

January through December 2017's Total births is 3293, total infant screened is 2856\*, total of infants diagnosed with hearing loss is 4, total of infants receiving early intervention services (EIS) is 1, and not receiving early intervention services is 33.

\*This represents a 99% initial screening rate at civilian birthing sites.

1 1 Relocated; 1 Refused

2 1 Relocated; 2 Lost to follow-up (LFU)

3 1 Refused; 1 Relocated; 1 Pending Enrollment

# 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 numerous 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.

• The High Risk Re-screening Clinic was moved to the Department of Public Health & Social Services Central Health Clinic. This was also a first step towards sustainability and strengthening our system of services.

• 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.

• The Guam EHDI Learning Community, consisting of parents of children who

are deaf and/or hard of hearing (D/HH), audiologists, pediatrician, Guam Early Intervention System Project Coordinator, Department of Education D/HH Coordinator, Nurses, Birthing Assistants and Nursing Supervisors, 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.

A picture of the Guam Early Hearing Detection Intervention website and for more information, visit www.guamehdi.org.

# Caleb’s Story

A picture of Caleb and mother smiling at camera.

Caleb Suzuki is not your typical eight-year-old. While most children would be ecstatic to visit a toy store, this is not the case with Caleb. According to Trisha Suzuki, Caleb’s mom, he loves office supplies. He loves to write, read and is a “social butterfly.” He entered the Special Education Preschool Program at three years of age and is currently a second grader at P.C. Lujan Elementary School. He is proficient in American Sign Language (ASL) and Signing Exact English (SEE). According to mom he has excellent teachers. He is currently mainstreamed into the second - grade class and utilizes the services and supports of a sign language interpreter. Trisha proudly shared how Caleb has an extensive vocabulary for his age and is academically on track with his peers.

Trisha Suzuki recalled that at four months of age Caleb fell ill with meningitis and was hospitalized in Intensive Care Unit for two to three weeks. This was a trying time for the family. While in the hospital, Caleb required a regiment of antibiotics, which led to a recommendation from his physician for further testing of his vision and hearing. She followed up with the recommendation for a hearing screening and had Caleb screened at Chief Brodie School. It was at this screening where Trisha found out that Caleb would require a sedated Auditory Brainstem Response (ABR) which Guam did not have at the time. The family then went off-island to have Caleb’s vision and hearing tested. The hearing evaluation revealed that Caleb had a profound hearing loss. Trisha shared how she was saddened when she received the news. The thought of her son never hearing her voice was overwhelming news for her. She remembers purchasing a sign language program shortly after learning of Caleb’s hearing loss. Trisha was determined to provide Caleb with as many resources available for children his age to develop language skills for effective communication.

Trisha’s long-term goal for Caleb is to have him attend Gallaudet University in Washington D.C. She has set a strong foundation for him to reach this goal in her efforts to advocate for her son at school, immersing him in as many activities such as the ASPIRE after-school program, summer camp, summer school, deaf camp, and the Deaf Church Community to name a few. These activities provide a multitude of life experiences for Caleb. He is a fearless young man who is ready to take on the world and is excelling in all that he does!

Trisha would like to see more parents of children with a hearing loss be active in the community and expose their children to more experiences. She would like Caleb to be part of the whole wide world for him to explore, learn from, and experience. She shared how because Caleb is so social, he thinks everyone knows how to sign. She believes the more interactions her child has with the deaf community as well as the community at large, the more confident he will be which will enable him to accomplish his dreams!

A picture of Guam Early Hearing Detection and intervention logo, University of Guam logo, and Guam CEDDERS logo.

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