



**2019-2020**  
**Guam Early Hearing**  
**Detection & Intervention**  
**(Guam EHDI)**

**Progress Report At-A-Glance**



# About Guam EHDl

The Guam EHDl 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. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA) to support Guam's Universal Newborn Hearing Screening Program. Guam EHDl also receives support through a Cooperative Agreement by the Centers for Disease Control and Prevention (CDC) to complement Universal Hearing Screening by implementing Guam ChildLink-EHDl, an integrated data tracking & surveillance system to support the Guam EHDl 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 EHDl 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;
- babies are enrolled in quality early intervention services by 6 months of age (known as the "1-3-6 Plan").

## 2017-2019 Hearing Screening, Diagnosis, & Intervention Data

Jan-Dec	Total Births	Total Number of Infants Screened	Total Number of Infants Diagnosed with Hearing Loss	Total Number of Infants Receiving Early Intervention Services (EIS)	Not Receiving EIS
<b>2017</b>	3293	2856*	4	1	3 <sup>1</sup>
<b>2018</b>	3176	2753*	3	0	3 <sup>2</sup>
<b>2019</b>	2697	2639*	2	1	1 <sup>3</sup>

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

<sup>1</sup> 1 Refused; 1 Relocated; 1 Pending Enrollment

<sup>2</sup> 2 Lost to follow-up (LFU); 1 Pending Enrollment

<sup>3</sup> 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 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 23 community outreach activities.
- Guam EHDI and the Department of Public Health and Social Services (DPHSS), continued to collaborate on the efforts toward interoperability between the Electronic Health Record (EHR) 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. GPPT lead Deaf Awareness Activities in September which included a Proclamation Signing at Adelup Governor's Complex, Deaf Awareness Wave at Paseo Loop, Deaf Awareness Outreach at Agana Shopping Center, Mass at Our Lady of Purification Church in Maina, and a Deaf Awareness Fundraising Dinner.
- GPPT also worked collaboratively with Guam EHDI to assist with the planning of the first Guam CARE Project Family Retreat for families with DHH children held on November 8-10, 2019. This retreat was lead by volunteers of the North Carolina CARE Project under the direction of Johnnie Sexton, Au.D. which provided families with emotional and audiological supports as families navigate the sometimes overwhelming system for their DHH child. They also assisted with the planning of the first SKI-HI Deaf Mentor Training held on January 16-18, 2020, to build the capacity of Deaf Mentors on Guam. This training was for DHH adults who are fluent in American Sign Language (ASL).
- The Guam Hearing Doctors implemented the "Shared Plan of Care" (SPoC) to be used for infants newly identified with a hearing loss. This SPoC includes medical and educational information for children identified with a hearing loss which parents can share with other professionals who care for their child.

# Mila's Story

Mila Quenga is a typical three-year-old girl who enjoys playing with blocks, running on a trampoline, and watching shows like Cocomelon, Vampirina, and the slow-motion videos squishing various toys on YouTube. Jamae Quenga and Milo Roberts Mila's parents limit her phone time and replace it with an activity to stimulate her mind. This description is typical for a three-year-old on our island, but Mila's story is atypical. Mila diagnosed with hearing loss and moderate to severe on the autism spectrum is DHH Plus.

Mila was born in 2017 and passed the initial hearing screening at the hospital. Since she was born at-risk for a hearing loss, the hospital requested Jamae to follow-up with an additional hearing test at six months. She believed the follow-up was a routine consult. Jamae's maternal instinct indicated a concern because she noticed that baby Mila did not react as expected when things fell and made a loud noise around her. When Jamae would sing to attempt to calm baby Mila, she would continue to cry. At her six-month follow-up hearing rescreening, Mila was referred for a Diagnostic Audiological Evaluation (DAE) to determine if a hearing loss is present. Mila was six-months when diagnosed with hearing loss. In 2019 she was also diagnosed with moderate to severe on the autism spectrum.

Mila received services from Guam Early Intervention Services (GEIS) in June 2018. She began Speech and Language Therapy in 2019 and is currently starting Occupational Therapy. She began attending daycare at the age of two and had difficulty adjusting to the new environment. Jamae was very hesitant for Mila in the daycare setting because of the concern with her headbanging. Jamae feels Mila has become accustomed to the routine because the staff tells her that she is getting better. Mila has her favorite teacher, yet it is comforting for Jamae to know that they are all getting to know Mila more and help to provide a safe and enjoyable place for her while both parents are working.

Jamae and Milo became involved with Guam's Positive Parents Together (GPPT) in 2018 and the Autism Community Together (ACT) in 2020. GPPT continues to provide support for her family. GPPT provides training and social activities for them to connect with other families who are experiencing similar challenges. During one of GPPT's social events, Jamae learned how to sign the primary colors from one of the American Sign Language (ASL) interpreters. Jamae knows that with GPPT, she is not alone. The parents are there to guide her family every step of the way between the Individualized Education Plan (IEP) meetings and learning ASL. She also learned that when Mila starts going to school, she will not settle for what is given at the IEP meetings if it does not meet her child's needs. She needs to fight for what Mila needs because she is her voice and knows her better than anyone else. The services received are helpful, but it has been a learning experience for them. Jamae and Milo are the primary caregivers for Mila. Since they are both employed, appointments are essential for Mila's progress; therefore, Mom is punctual and expects the agencies to have professional support. As parents, they strive to provide the best care available for their daughter. In the beginning, Jamae felt she could only confide in her spouse about her concerns with Mila's condition. She now feels counseling for parents would be helpful, and efficiency on the agency's part would be beneficial for everyone. Jamae and Milo are appreciative of the services received for their daughter and are still in the process of learning themselves.



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