



2018-2019
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 (HSS), 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;
- quality early intervention services babies need are initiated by 6 months of age (known as the "1-3-6 Plan").

2016-2018 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 |
|-------------|--------------|----------------------------------|---|---|-------------------|
| 2016 | 3440 | 2984* | 4 | 1 | 3 ¹ |
| 2017 | 3293 | 2856* | 4 | 1 | 3 ² |
| 2018 | 3176 | 2753* | 3 | 0 | 3 ³ |

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

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

² 1 Refused; 1 Relocated; 1 Pending Enrollment

³ 2 Lost to follow-up (LFU); 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 21 community outreach activities.
- Guam EHDl 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 - EHDl.
- Efforts continued to strengthen the data collection and reporting system in preparation of the long-term goal of turning ChildLink - EHDl over to system partners.
- DPHSS, in collaboration with Guam EHDl, 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 EHDl which also strengthens tracking and surveillance efforts.
- A Memorandum of Agreement was finalized and executed with Guam's Postive Parents Together, Inc. (GPPT) a local nonprofit organization to implement the parent engagement component of Guam EHDl-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 occurred which helped the group establish relationships to support one another.
- The Guam EHDl 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.



For more
information, visit

www.guamehdi.org

Gåtbo's Story

Wil and Evelyn Topasna had mixed emotions when the ultrasound of their unborn child showed he had a cleft lip. They were scared, sad, and worried when they first found out but felt fortunate to know beforehand as this helped them prepare for his arrival. Through prayers, they were able to accept and embrace the news and embarked on a mission to do everything they could to help their child meet his full potential.

Gåtbo Topasna was born with several challenges. The focus of attention at birth was his cleft lip and palate. Not long after leaving the hospital they noticed that something was off with his hearing, their pediatrician referred Gåtbo to Guam Early Intervention System (GEIS) to receive early intervention services. Evelyn shared how blessed they were to have GEIS by their side from the beginning of their journey. Gåtbo was only a few months old when he saw an ear, nose, and throat doctor. The doctor confirmed that he needed to get his hearing tested. Wil and Evelyn pushed for his testing, however, encountered some challenges to get a definite diagnosis. It took a while for them to see an audiologist. Gåtbo was a little over a year old when it was confirmed that he had a severe bilateral hearing loss. He received his first hearing aids at age four just in time for him to start attending the Head Start Program. Evelyn expressed how lucky they were that Gåtbo accepted the hearing aids in his ears and made no attempts to take them off. It was a smooth process for all of them.

Gåtbo is now an eleven-year-old boy, who strives to do his best and is fluent in speaking CHamoru and English. His current passion is to learn American Sign Language (ASL). He wants to be able to communicate with his friends who sign as he admires their ability. He enjoys swimming, watching sports, and playing "Minecraft" and "Dream League Soccer" on his Ipad. His love for soccer led him to play for the Southern Cobras. One of his many talents is quickly solving any iteration of the Rubiks cube, even with his eyes closed!

Gåtbo is currently a fifth grader at Harry S. Truman Elementary School. He receives Speech Therapy and consultation for Occupational Therapy services which consists of a collaboration between parents and teachers on strategies for Gåtbo to be able to function in the classroom due to limited arm movement.

As parent mentors of Guam's Positive Parents Together, Inc. (GPPT)/Project Fitme, Wil and Evelyn provided the following advice to parents: 1) be not afraid to ask questions; 2) do your research; 3) understand your child and their needs because everybody is different; 4) and most especially, discover what is needed for your child and your family. Wil and Evelyn also shared the benefits of being in the GPPT/Project Fitme Parent Support Group, a newly formed Parent Support Group for families of children identified with a hearing loss. According to Wil and Evelyn, "It is reassuring when families hang out together and talk with those who have the same or similar issues. It is a special community where families are working towards the same goal." Evelyn shared how she was able to attend different types of training to guide her along the way. Wil and Evelyn hope that the parent support group will be able to connect with more families to experience the same feelings of not being alone and will always have someone to turn to whenever they have any questions. Families will also learn that there are many options to consider to best meet the needs of their child with a hearing loss.



Guam EHDH

Phone: 735-2466 TTY: 734-6531

Email: nenihearing@guamcedders.org

Location: Dean Circle House 22, University of Guam

Produced by the Guam Early Hearing Detection and Intervention (Guam EHDH) Project with 100% funding support from the U.S. Department of Health & Human Services, Centers for Disease Control and Prevention, Grant No. 5NUR3DD000093-02-00 and facilitated by the University of Guam Center for Excellence in Developmental Disabilities Education, Research, & Service (Guam CEDDERS).

The University of Guam is an Equal Opportunity Provider and Employer.