

New CDC EHDI Competing Continuation- Project Title: *Guam ChildLink*
ABSTRACT

This Cooperative Agreement application responds to CDC-RFA-DD17-1701, Centers for Disease Control and Prevention (CDC)/Agency for Toxic Substances and Disease Registry (ATSDR), “Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS).” The title of the project is *Guam ChildLink (GCL-EHDI)*, the tracking and surveillance system developed for Guam EHDI, through 14 years of CDC funding, to support the National EHDI Goals. *GCL-EHDI* is an EHDI-IS, as it routinely collects and reports valid, verifiable, unduplicated, individual level data on all civilian births on Guam.

GCL-EHDI began in 2003 as a stand-alone system and has evolved into a fully developed web-based tracking and surveillance system with over 200 data fields that can generate 25 different types of reports and interactive lists. *GCL-EHDI* provides critical data to collaborative partners to ensure all infants born on Guam receive a hearing screening before one month of age, and all infants who are diagnosed with a hearing loss are receiving early intervention services in a timely manner. It is the pioneering database system that officially shares data electronically with key early childhood serving organizations including four GovGuam agencies, a private hospital, and a private birthing center, and has been a model for electronic data exchange for other programs on Guam.

GCL-EHDI aims to implement five key strategies designed to further improve the documentation of timely follow-up diagnostic testing and early intervention services, in order to support the early identification of Deaf and Hard of Hearing infants and help address potential developmental delays. The intention of this next grant cycle is to support jurisdictions that have screened 90% or more of infants in calendar year 2015, have routinely identified deaf and hard of hearing (D/HH) infants, and have demonstrated challenges in providing and documenting follow-up testing and intervention. This Cooperative Agreement will continue to provide support for the maintenance and further enhancement of EHDI-IS, which serves as a powerful tool to help programs to ensure that all infants receive a hearing screening and recommend follow-up diagnostic and intervention services. Without the recommended follow-up services, D/HH infants cannot be identified early and are at risk for developmental delays. The benefits of newborn hearing screening are highly diminished when recommended and timely follow-up services are not provided to infants in need.

The strategies of this *GCL-EHDI* project include: 1) Surveillance to implement a complete EHDI-IS. 2) Training and support to provide training and technical assistance to address the needs of state partners involved in the EHDI reporting processes. 3) Partnership to promote and support coordination and collaboration around capturing data. 4) Communication and dissemination to support targeted dissemination of data and information among stakeholders. 5) Monitoring, analysis and evaluation to maintain data quality and guide programmatic improvement.

The Guam EHDI project, through *GCL-EHDI*, will continue to improve the capacity of their current EHDI-IS to collect complete, accurate, and valid data on follow-up hearing screening, diagnostic testing and early intervention, in accordance with Goals 2-8 of the CDC EHDI-Is Functional Standards

HRSA EHDI

Abstract

The Guam Early Hearing Detection and Intervention (Guam EHDI) Project has facilitated universal newborn hearing screening on Guam since 2003. The project has guided the development of a comprehensive and collaborative system in achieving a systematic process that ensures that all babies born on Guam receive a hearing screening before they leave their birthing facility. Partnering with the three civilian birthing sites, and the Department of Public Health and Social Services and the Guam Early Intervention System, Department of Education, Guam EHDI has facilitated the implementation of the 1-3-6 requirement of hearing screening of infants by one month, diagnostic evaluation by three months, and receiving early intervention services by six months of age. In addition, a comprehensive tracking and surveillance system has been established to ensure that all infants are not lost to follow up. A major challenge has been related to meeting the three-month diagnostic evaluation for infants referred due to a lack of consistent access to audiological services. Parent engagement has also been a challenge.

To address the continuing need to further develop this system, the proposed Guam EHDI-Fitme Project aims to work towards the Overall Program Goal to support the development of a statewide program and system of care that ensures that deaf or hard of hearing children are identified through newborn and infant hearing screening and receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy, and social-emotional development. Program goals are: 1: Increase health professionals' engagement within and knowledge of the EHDI system; 2: Improve access to early intervention services and language acquisition; and 3: Improve family engagement, partnership, and leadership within the EHDI programs and systems.

Program Objectives: By April 2020, the end of the three-year project period: 1) Increase by 30% from baseline the number of newborns and infants who receive timely diagnosis per Joint Committee on Infant Hearing (JCIH) recommended practice guidelines by the end of the three-year project period; 2) Increase by 25% from baseline the number of newborns and infants who receive timely referral to EI per JCIH recommended practice guidelines by the end of the three (3) year project period; 3) Increase by 20% from baseline the number of newborns and infants identified to be deaf or hard of hearing enrolled in EI services within JCIH recommended practice guidelines by the end of the three (3) year project period; 4) Develop partnerships supported by a memorandum of understanding with identified statewide, family-based organizations or programs that provide family support to families/parents/care-givers of newborns and infants who are deaf or hard of hearing by the end of the three (3) year project period.