



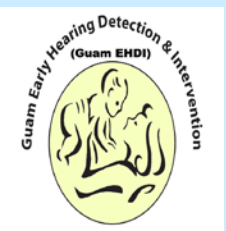
EHDI Profile for the Territory of GUAM

**A Presentation for the CDC Site Visit
September 9 & 10, 2008
Guam CEDDERS-Hs. 26
The Marriott Hotel**



Organization of The Presentation

- I. Program Information: Review & Update
- II. Hearing Screening of Newborns: Status from 2005-2007
- III. Diagnostic Evaluations (DAEs): Status from 2005-2007
- IV. Early Intervention
- V. Late Onset, Progressive, and Acquired Hearing Loss
- VI. Medical Home
- VII. Tracking & Surveillance: Minimizing Loss to Follow UP
- VIII. Involving Stakeholders in Coordination of Care
- IX. Monitoring and Evaluating the Guam EHDI System
- X. Resource Materials, Training, and Public Awareness
- XI. EHDI Pacific Regional
- XII. Other Issues
- XIII. Summary of Progress Made Since CDC Site Visit-Feb. 2006



I. Program Information



Location:



- The Guam EHDI Program is located at Guam CEDDERS House 24 & 26
- Primary Contacts: Dr. Heidi San Nicolas, Principal Investigator for both HRSA & EDHI Cooperative Agreements
- Guam EHDI Website: www.guamehdi.com
- State Advisory: Guam EHDI Advisory Board with 24 members (Listing provided)



Funding

Federal: HRSA & CDC Cooperative Agreements

Local: None. Guam EHDI staff continue in the plan to develop local sustainability for the EHDI program once federal support discontinues



Hearing Screening Protocols

- *Does Guam have written guidelines/protocols for performing hearing screening?*
- **YES**, DPH&SS has adopted the Guam EHDI Resource Manual as the Standard of Care.
- Guam EHDI Resource Manual is available for review



Standard of Care

- Is newborn hearing screening part of all birth sites standard of care package? **YES**. Is informed consent required? **NO**-after the passage of PL 27-150 (UNHSIA) both birth sites made hearing screening part of their Standard of Care package.



Technology & Performance

- *What screening technology do you use?*
Guam continues to use the Grayson-Stadler GSI-70 for OAE Screening.
- *Who does the screening at the birth sites?*
Nurses, Nurse Aides, with periodic monitoring by the Guam EHDI Hearing Screening Technician
- Who does out-patient screening? **Guam EHDI Hearing Screening Technician, Central and Southern Public Health Clinic Nurses and Nurse Aides.**

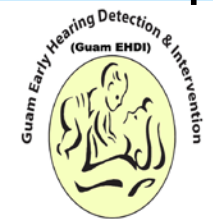


Rescreen & High Risk



*If a baby does not pass the screening, what procedures are followed?
To whom is it reported?*

- Prior to discharge, the parents are given a rescreen appointment to return for a 2nd screen
- Results are reported to parents and the infant's pediatricians
- For infants with HIGH RISK factors, the infant is referred to Guam Early Intervention (GEIS) and rescreen is performed in 6 months
- The list of infants with HR factors is now generated by Guam ChildLink and linked the GEIS for continued monitoring



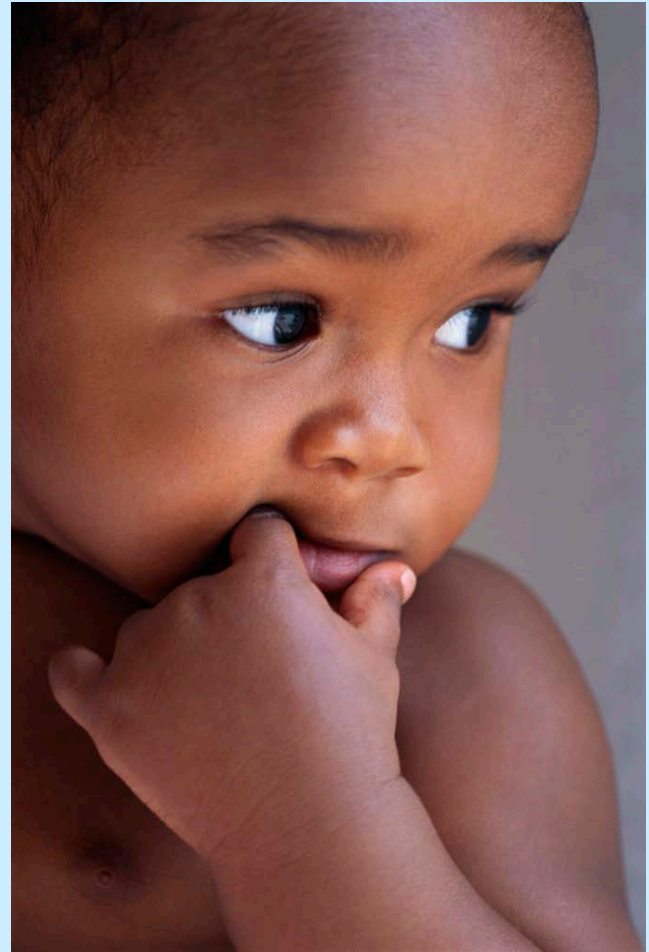
Rescreen Responsibility

- Who is responsible for setting up the appointment for rescreen?
- How soon does the baby usually come back?
- Birthing sites schedule the rescreen appointments
- Infants usually return for a rescreen in 2 weeks



What equipment is used for out-patient screening?

- The Grayson-Stadler GSI-70 and Guam EHDI is now testing the use of AUDX-PRO based on the recommendation of NCHAMS consultant
- Equipment is calibrated and new equipment is purchased yearly



What happens to infants born outside of a hospital, do they receive hearing screening?

- No home births have occurred on Guam recently, but births en route receive a hearing screening once transported to GMHA
- Well baby clinics, referrals from pediatricians or self referral are other avenues for screening infants who are not born on Guam

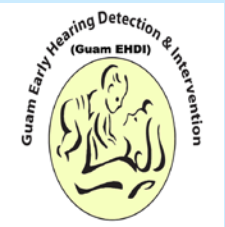


What are key issues facing Guam that affect screening infants for hearing loss?

- Loss to follow up-Return for 2nd screen, return of infants with HR factors, issues related to late onset for hearing loss.
- Parental refusal for early intervention services
- Electronic birth certificate for Guam
- Military reporting of infant hearing screening to Guam ChildLink
- Reluctance of some families in agreeing with audiological evaluation results



II. Diagnostic Evaluations (DAEs)



Audiological Assessment Protocols

- Does Guam EHDI have required or recommended audiological assessment protocols or guidelines for personnel, facilities, and equipment?
- YES, protocols can be found in the Guam EHDI Resource Manual



Pediatric Audiologist

- ***Is there a Guam list of pediatric audiologists or diagnostic center?***
- ***Does Guam EHDI have medical assessment protocols or guidelines?***
- ***Who does the audiologists send the report to?***
- Guam now has 3 audiologists, one in private practice, one who serves the Guam Public School System, and a newly arrived pediatric audiologist
- No, Guam does not have medical assessment protocols or guidelines but has published an FAQ for Medical Professionals
- Reports from the audiologist are sent to the family, pediatrician, and the Guam EHDI project. Guam EHDI is now linked electronically to the audiologist in private practice



Part III. Early Intervention



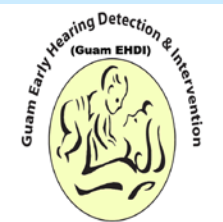
Lead Agency & Eligibility

- Who is the lead agency for Early Intervention Services?
- Are infants with mild and unilateral hearing loss eligible?
- Guam Public School System-GEIS is housed at UOG Deans Circle
- YES, if infants have any type of hearing loss they are eligible for early intervention services



What is the eligibility criteria for children with hearing loss to received early intervention through Part C?

- **GEIS**
 - 4 Eligibility criteria
 - Establish Risk (known mental or physical condition)
 - Biological At Risk
 - Environmentally At Risk
 - Developmental Delay
- **EDIS – must qualify under DODEA**
 - Eligibility Criteria
 - Developmental Delay
 - 20% in 2 areas
 - 25% in one area
 - Biological Risk or Established Condition



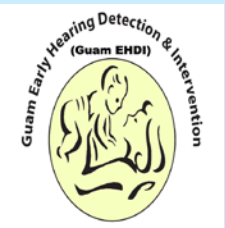
Early Intervention Linkage

- Does the GEIS report enrollment and intervention information back to Guam EHDI?
- YES. GEIS is now electronically linked to Guam ChildLink and data is shared on all infants with hearing loss and those with high risk receiving early intervention
- Hearing Screening Technician also meets with GEIS Director every month to review the list of infants with high risk factors and insure 6-month follow up



Preschool Programs

- Does Guam EHDI receive information/reports from preschool programs?
- Not at this time. Guam EHDI relies on reports from Division of SpEd when young children transition under Part B and the IFSP later becomes an IEP to assure follow up.



Tracking



- Does the Guam EHDI program track the type and intensity of EI services received by infants, children, and their families? To what age do you track children identified with hearing loss?
- Children with hearing loss are tracked by the Guam EHDI project until they transition to Part B at age 3.

What kind of services are available to preschool children with hearing loss on Guam? Where are the children served?

- Speech and Language Services
- Specially designed instruction
- Preschool Children with hearing loss are served in Head Start Centers or SpEd Preschool Classes.
- Parent Information Resource Center (PIRC)



V. Late Onset, Progressive, and Acquired Hearing Loss



Does the EHDI program on Guam collect data on known risk factors? If yes, are the JCIH risk indicators used?

- Guam does collect data on known risk factors that are similar to the JCIH risk indicators. It was recently updated and provided to GEIS
- There is also a poster on high risk infants that has been developed to assist families.
- Guam will require TA assistance in CMV issues for health care professionals and early intervention staff.



What follow-up procedures do you use for infants with risk factors for hearing loss?

- Infants with risk factors are rescreened at 6 months of age.
- If they pass the rescreen, no further screening is required.
- Under GEIS, If they fail the rescreen twice, the infant is referred for a full audiological evaluation and results are reported electronically to Guam ChildLink



VI. Medical Home



How does Guam's surveillance system integrate with the medical home to ensure tracking and follow-up?

- Working with GEIS, Guam ChildLink will update an infant's status from reports provided by GEIS to ensure tracking and follow up. This information is in a brief comment section on the Early Intervention file on Guam ChildLink
- Guam ChildLink identifies the infant's Medical Home and status of medical follow-up, as described above.
- In the next grant cycle, expansion of how the database can support relevant data collection for Medical Home will be explored.



VII. Tracking and Surveillance that Minimizes Loss to Follow-Up



What software and database system does the Guam EHDI program use to track hearing screening, diagnostic and intervention data?

- Guam continues to use the Microsoft SQL with a server that will allow the birthing sites the option of downloading their data to a server that is protected with firewalls and accessible only to EHDI users.
- Plans to expand to a web-based system has not continued as current direct linkages are proving more feasible



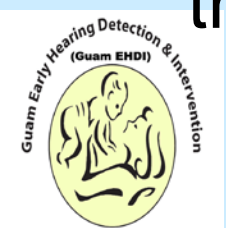
How is an infant uniquely identified in the Guam EHDI tracking system?

- The database has 2 types of numeric identifier:
 - (1) the Guam EHDI numeric string and
 - (2) the hospital record number or birthing site's unique numeric string
- These have proved to be sufficient and useful, particularly with electronic linkages.



Does the Guam EHDI program receive reports from hospitals, physicians, audiologists, EI? If so, how are these reports received?

- The hearing screening results for each infant is currently reported electronically with each birth site having access to Guam ChildLink
- Reports from the audiologist in private practice is also electronically linked at this time. Any reports from physicians are either faxed or hand carried from the site to the EHDI program. While there are no links to the physician, in the next cycle, Guam EHDI will pilot the linkage with the State Champion's office to model the effectiveness of this option for other medical homes.



Does Guam maintain a registry of children diagnosed with a hearing loss? If so, up to what age?

- Guam maintains a registry of children with diagnosed hearing loss on Guam ChildLink and aggregate reports can be generated.
- With the GEIS linkage now in place, follow up can now be done both electronically and in contact meetings with GEIS.



Are children that are identified by means other than the newborn hearing screening program, entered into the Guam EHDI data base?

In the event an infant is identified by means other than the birth site, (it assumes this infant was missed by the newborn hearing screening program) then, the infant data will be entered into the database and noted that identification was not done via the newborn hearing screening program.



Do you currently integrate with other data systems and if so, which ones? Do you have written policies/agreements for data sharing?

- Linkages are now in place with both birth sites, the audiologist, and early intervention
- Linkages with Northern and Central Public Health is being negotiated and will be in line by 2008-2009
- No linkages are in place with metabolic screening or CWSHCN programs as databases have not been developed for these programs.



Do you currently prepare data reports or a published report that you share with the hospitals, advisory committee, audiologists, legislature, EI, or the public?

- Yes, formal data reports, usually in the form of a PowerPoint presentation are provided to the Guam EHDI Advisory Council at their quarterly meetings and this report is also shared with the Guam Interagency Coordinating Council.
- Formal reports are being drafted at this time as “Guam ChildLink Update” and will be disseminated to the birthing sites and other stakeholders who will be integral to the process of transition and funding once grant funds are concluded.
- Informal data reports are shared with the GEIS, and the Guam EHDI parent support group.
- The Guam EHDI program periodically provides short reports to the public via public service announcements, newsletters, or other media, when requested.



What security systems are in place to maintain the confidentiality of collected data?

The current data system is not connected to the internet, is password protected, and hardcopy files are double locked in the Guam EHDI office.

- In addition, a dedicated DSL line is used to transfer data.
- The ChildLink data system, has firewall protection, data encryption, password protection and uses locked files. This has not changed.
- With the passage of the public law on hearing screening as part of standard of care, parents no longer have to sign consent forms for screening, but do so when referral is made for early intervention services. All HIPPA and FERPA requirements are full integrated into this process

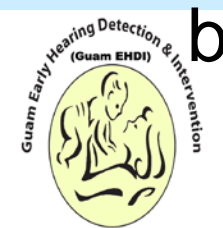


VIII. Involving Stakeholders in Coordinator of Care



Who are your primary stakeholders / collaborators and what challenges does Guam EHDI face regarding the involvement of stakeholders?

- The primary stakeholders are represented in the Guam EHDI Advisory Council, Guam EHDI Family Support Group, and the Guam Interagency Coordinating Council.
- A major challenge has been the availability of a pediatric audiologist (PA), but with the arrival of a PA on island, this issue has been addressed.
- Buy in to the Medical Home model continues to be of concern to the project



Have your stakeholders help you to achieve the goals of the Guam EHDI Program? If so, please provide an example of how they have support you.

- The Parent Information Resource Center (PIRC) was the successful collaboration of parents, spearheaded by parents in Guam EHDI
- A Power Meeting was held on August 7, 2008 with relevant stakeholders on the need for an electronic birth certificate process for Guam
- The Guam EHDI Family Support group participates in outreach activities

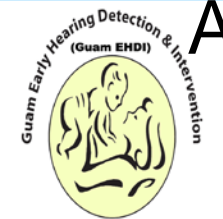


IX. Monitoring and Evaluating the Guam EHDI System



What types of activities are you currently doing to monitor/evaluate the EHDI systems?

- Quarterly reports to the Guam EHDI Advisory Council
- Monthly meeting with GEIS
- Periodic meetings with the Clinical Audiologist is conducted regularly to ensure audiological follow-up and hearing aids assessment and management
- Will develop an analytical plan for evaluating Guam ChildLink as part new grant goals.
- Will complete the draft of the EHDI Quality Assurance



Does the Guam EHDI program monitor performance of individual hospital screening programs? If so, is feedback provided to the hospitals?

- Yes, screener referral rates are monitored carefully at each of the birthing sites.
- Feedback is given to nursing supervisor on a monthly basis to monitor performance of individual screeners.



Is Guam using any surveys to obtain feedback from parents, physicians, EI programs, hospitals, audiologist?

- At the current time, surveys are conducted with parents/ service providers when training is provided.
- After re-screens, parents are provided a satisfaction surveys are completed.



Are you matching data with any population-based reporting system? (such as metabolic/blood spot, vital records/birth certificates)

- Yes, cross checks are performed with the birth log with the hearing screening data
- There are plans to match hearing screening data with the birth certificate registry once DPHSS initiates electronic birth certificate

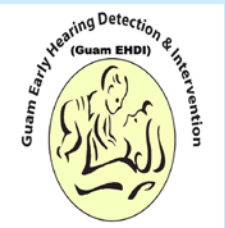


Does Guam have a written EHDI program evaluation plan?

- Yes, the program evaluation is described in both the MCHB and CDC grant applications.
- Evaluation procedures include:
 - Engaging stakeholders in the evaluation
 - Describing the surveillance system in the evaluation process
 - Initiating and carrying out the quality assurance plan



X. Resource Materials, Training, and Public Awareness



Do you provide a list of resources and contacts that discuss the various communication options to enable families to make informed decisions?

- Guam EHDI updated the Directory of Services including electronic online resources for parents and service providers.
- Guam Early Intervention System reviews resources and options
- Guam EHDI website lists resources
- Guam EHDI Family Support Group connects with families for support



What educational materials do you provide to other stakeholders and the public?

- Guam EHDI Project updated Directory Resources
- Other education materials developed include the following:
 - Brochures
 - Posters
 - Pamphlets
 - CD-ROMS
 - Public Service Announcements
- Guam EHDI staff participates in a variety of outreach activities.



What trainings/seminars/conferences are provided by the Guam EHDI program? For whom?

- Training/Seminar/Conferences
 - Hearing Screening Training
 - Nurses @ birthing sites (GMH, SM)
 - Nurses @ Public Health
 - GEIS Staff
 - Community Outreach Presentations
 - Guam EHDI Family Support Group



What challenges does your program face regarding increasing awareness about the Guam EHDI?

- Cultural and language barriers
- Transportation issues
- Cultural beliefs and differences
- Denial/avoidance



XI. EHDI Pacific



Do you have any experience working with families who travel to this country looking for help for their children with hearing loss? Are these children included in the Guam EHDI database?

- Yes, Guam EHDI provides assistance and support to the Federated States of Micronesia, Republic of Palau, Republic of the Marshall Islands, Japan, Korea, China, Indonesia, and other Asian countries.
- All infants screened on Guam are included in the database



How do you work with non-English patients who have low proficiency in English? For e.g. how do you inform them about the Guam EHDI process (screening, evaluation and early intervention)? Do you have multilingual staff who are able to communicate with these patients and guide them through the Guam EHDI process?

- Guam EHDI provides both translated brochures and native speakers of Pacific languages who interpret information to multi-lingual families to ensure that families understand the Guam EHDI process. The Guam EHDI staff have Chamorro and English speakers only, however translators are available through various units on the UOG campus, such as the Micronesian Language Institute and the English Language Institute.



Could you please describe the language, cultural, or any other barriers your state has when attempting to reach minority populations with hearing loss?

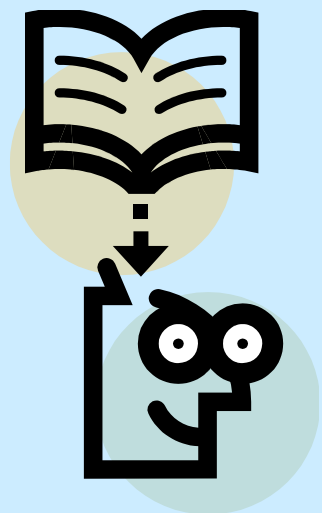
- Language barriers are not as problematic as the cultural belief system that must be overcome,
- The belief that a newborn infant should not be taken out into a public place before they have been baptized or other ritual is performed to “protect” them is sometimes a problem.
- Some cultures believe that an infant will outgrow a problem and intervention is intrusive and not necessary.
- The notion of “shame” or “denial” that a problem may exist continues to be a barrier to provision of early intervention services.



EHDI Pacific Meeting

- Plan are in the works for a Pacific Regional Meeting after the EHDI National Meeting in Dallas, Texas





XIII. Other Issues

What funds are available for screening, audiological evaluations, Early Intervention, hearing aids, other assistive devices, and cochlear implants?

- Funding for audiological services and early intervention is provided by the Guam Public School System -Part C funds
- For hearing aids, assistive devices, and cochlear implants, funds are available only through private insurance coverage



Other issues:

- U.S. Naval Hospital Guam does not report hearing screening data to Guam EHDI. Guam EHDI needs a resolution to this issue which has lingered for 3 years
- Lack of a resource pool to draw on for audiological services, speech & language services, and other health care needs
- Lack of experts in the different communication methodologies which limits family's options.



XIII. Summary of Progress Made Since CDC Site Visit Feb. 2006



Progress Summary

February 2006

- Website Plan
- Promulgation of Rules and Regulations
- DPHSS Screening Training and Linkage Plan
- Linkages to GMHA, Audiological Associates, GEIS Planned
- High “false positive rate” was a problem
- No Pediatric Audiologist
- No backup server

September 2008

- Website now in place
- Promulgation Completed
- Implemented DPHSS Training
- All linkages completed
- Problem reduced through ongoing training and monitoring
- Now ONE walking on-island Guam– SOON to be on-board 😊
- Backup server to be installed by 9/30/08

