



CDC Early Hearing Detection and Intervention Program
Annual Progress Report-Year 1
July 1, 2008 – June 30, 2009

Name of Awardee: University of Guam-Center for Excellence in Developmental Disabilities:
Educational, Research, and Service (Guam CEDDERS)
Award Number: DD08-803, Early Hearing Detection and Intervention (EHDI) Tracking,
Surveillance, and Integration
Principal Investigator: Dr. Heidi San Nicolas
Project Director: Dr. Velma Sablan & Joseph Mendiola- Data Coordinator
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SECTION 1: Background and Updates Narrative: The Guam EHDI data tracking and surveillance system, referred to as Guam ChildLink began development in 2003 and has been in a continual process of improvement and refinement, working toward the goal of becoming a fully integrated, collaborative database system supported by partnerships with the Guam Department of Public Health and Social Services (DPHSS) Bureau of Family Health and Nursing Services, Maternal Child Health (MCH) Program, Guam Memorial Hospital Authority (GMHA), Sagua Mañagu Birthing Center, Audiological Associates, the Guam Public School System - Guam Early Intervention System (GPSS-GEIS) and the University of Guam, Center for Excellence in Developmental Disabilities Education, Research and Service (Guam CEDDERS).

Guam ChildLink continues to collect initial and follow-up hearing screening data from two of the three birthing sites on Guam, this includes GMHA and Sagua Mañagu Birthing Center. Data on infants found with potential hearing loss are tracked and monitored to ensure timely Diagnostic Audiological Evaluation (DAE) and referral to the early intervention program. Currently, the Guam EHDI Project does not receive or report any data from the U.S. Naval Hospital (USNH), the third birthing site on Guam. A major focus of the current 3-year grant cycle continues to be on data management to support the 7 following areas: 1) Ensuring no duplication of data occurs particularly between the birthing sites, Sagua Mañagu and GMHA. Sagua Mañagu is a birthing center that does not accommodate infants with any level of medical complications or risks. High risk babies are transferred to GMHA. In this transfer hearing screening may be overlooked and / or duplication may occur; (2) Expanding of data fields collected at each level, especially by early intervention services to improve comprehensive services and timely follow-up to infants with hearing loss and their families; (3) Reducing lost to follow-up and improve the tracking of late on-set through Guam ChildLink; (4) Developing and piloting electronic linkages with the Medical Home using data fields relevant and needed; (5) Interfacing with the birth certificate process and other reporting sources to ensure tracking of all infants born on Guam; (6) Expanding data fields for parent-to-parent support systems; (7) Expanding and refinement of various types of reports relevant to needs and issues for national reporting on Guam and to continue developing new inquires and trend analyses to expand the usefulness of the tracking system. This annual progress report will describe the progress of the Guam EHDI goals and objectives for Year 1: July 1, 2008 to June 30, 2009.



Section 2: Goals and Objectives Narrative: This section will begin with Table 1 which gives an overview of progress made in all project goals and objectives for Year 1. Table 1 is organized with each major goal listed, followed by all corresponding objectives, and a 4-quarter percentage scale from 25% to 100% to indicate level or completion for Year 1. Progress levels were determined based on activities completed during the Year 1 period. A narrative section for each goal is provided which describes additional details on progress made for each goal since the last reporting period.

Table 1. Overview of GuamEHDI-SER Goals & Objectives: Performance Levels for Year 1

<i>Summary of Progress Year 1</i>	Percentage of Accomplishment			
	25%	50%	75%	100%
GOAL 1: Guam EHDI will enhance and improve methods to accurately identify, match, and collect unduplicated individual identifiable data and secure web reporting.				
Objective 1.1 Enhance Guam ChildLink through expansion of data fields relevant to the needs for Guam, by conducting data file analysis of all infants identified with hearing loss to determine if infants were identified and provided services within appropriate timelines and to identify gaps in service				
Objective 1.2 Troubleshoot the electronic linkages at the birthing sites to ensure precise transfer of data, no duplications, and secure electronic reporting by conducting quarterly reviews to ensure quality performance and continue negotiations with U.S. Naval Hospital for data reporting				
Objective 1.3 By the end of Year 1, review and revise the Guam ChildLink technical manual in collaboration with all stakeholders.				
GOAL 2: Guam EHDI will collaborate with reporting sources to develop an GEHDI reporting protocol for all involved agencies in order to increase data sharing, integration, and linkage				
Objective 2.1: Amend existing Memorandum of Agreements (MOAs) each year as needed to document any collaborative modifications for data sharing integration and improved linkage. Other data sources on Guam include: DPHSS Metabolic Screening, GPSS Division of Special Education Child Find, DPHSS MCHB Children with Special Health Care Needs, Child Care Centers, GPSS Head Start, GPSS GEIS.				
Objective 2.2: Develop reporting protocols at all levels where data sharing, integration and linkages exist, and initiate new protocols for newly developed linkages. Protocols for GMHA, Audiological Associates, Naval Hospital, Medical Home, and DPHSS Community Health Centers will be completed by the end of Year 1.				
GOAL 3 Guam EHDI will continue to monitor the status and progress of every occurrent birth on Guam.				
Objective 3.1 Guam EHDI will continue to conduct monitoring of initial screening prior to discharge or within 1 month, to insure every infant born on Guam has a hearing screening test.				
Objective 3.2 While methodologies for decreasing loss to follow up at all levels continue, Guam EHDI staff will also conduct random case analyses each quarter in three categories: (1) Lost to Follow-Up Re-screening, (2) Lost to Audiological Follow Up, (3) Infants with hearing loss and not receiving early intervention services to determine gaps in service; and (4) Infants with hearing loss and receiving early intervention services to determine gaps in follow-up medical or audiometric services.				
Objective 3.3 Publish and disseminate an annual report of Guam ChildLink which gives both aggregate and anonymous case specific information to key stakeholders				



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including policy makers, agency Directors Health Care professionals, and other community involved decision makers.				
GOAL 4 Guam EHDI will report standardized aggregated hearing screening information, including ear specific diagnosis, maternal demographics, date of diagnosis, and information on early intervention service data.				
Objective 4.1 Guam EHDI will continue to participate in monthly National teleconference meetings to stay current in any new or modified CDC reporting requirements.				
Objective 4.2 Each year review and increase options for the community and region to access relevant Guam EHDI resources, data, and materials, especially the DPHSS MCH Children with Special Health Care Needs Coordinators through the Guam EHDI website.				
GOAL 5 Guam EHDI will improve and enhance identification and collection of standardized data on infants and children with late onset or progressive hearing loss and continue to develop an analytic plan to address loss to follow up rates This activity will align with a quality assurance and improvement system to be developed simultaneously during the grant cycle.				
Objective 5.1 Guam EHDI will improve and enhance identification and collection of standardized data on infants and children with late onset or progressive hearing loss and continue to develop an analytic plan to address loss to follow up rates This activity will align with a quality assurance and improvement system to be developed simultaneously during the grant cycle.				
Objective 5.2 Conduct a quarterly in-depth case analysis of all children found to have late onset of hearing loss and generate any gaps or weaknesses in the system which could have resulted in earlier identification and/or develop new data fields which could have resulted in earlier identification.				
Objective 5.3: Continue to document findings from yearly data analyses activities to begin the formative procedure for the development of a long term quality assurance plan for Guam ChildLink.				

PROGRESS NARRATIVE FOR GOAL 1: The quality and accuracy of data in Guam ChildLink continues to be monitored through the following methods: 1) On a monthly basis, the Data Coordinator prints out data reports and verifies accuracy to ensure there are no duplicate files. 2) The office technician cross-checks data using the hard copy of the hearing screening results from the birthing sites to ensure accuracy of data electronically transmitted into Guam ChildLink. 3) If there are discrepancies, the Data Coordinator reviews the files and make the necessary corrections into Guam ChildLink. 4) Each agency is linked to the Guam EHDI server through a virtual private network. Once connected to the Guam EHDI server, they are linked to the Guam ChildLink system via a remote desktop connection. There are double firewalls in place before gaining access into the Guam EHDI server. The Project Director and Coordinator completed the 2008 case extraction and analyses of all infants identified with hearing loss. A copy of the findings can be found in Attachment 1. Upon analysis of cases, additional user fields, reports, and interactive lists have been added to the Guam ChildLink in order to provide detailed information. For example, the high risk pull down menu was refined so that general categories are now more defined, also, a user specific report was created for Sagua Mañagu birth site to monitor aggregate data of infants from initial screening to diagnostic audiological evaluation (DAE).



The GMHA electronically uploads data of all babies born and the results of the hearing screening to the Guam EHDI server on a weekly basis. This file is reviewed and cross checked by the off-island consultant to ensure accuracy of the uploaded files. If there are errors in the files, the Hospital Information Technology Administrator at GMHA is notified and the necessary changes are made to those files. If and when the file is complete, it is translated and uploaded into the Guam ChildLink. Sagua Mañagu Birthing Center links directly into the Guam EHDI server and inputs infant data directly into Guam ChildLink. Records are verified with hard copies by the office technician. Significant progress has been made under these activities. USNH averages around 400 births a year, however, does not provide data of infants screened to the Guam EHDI Project. The USNH early intervention program also known as the Education, Development, and Intervention Services (EDIS) program are members of the Guam EHDI Advisory Committee and have requested for a meeting with the new USNH Commander to discuss the possibility of participating in the Guam EHDI Project. Progress continues on Activities 1.2.1 and 1.2.2. In addition to verification of the files uploaded from GMHA by the off-island consultant, the Data Coordinator conducts a bi-weekly data review to ensure the information transmitted from both birthing sites are accurate and there are no duplications. Hard copy data received is matched with infant data electronically transmitted. There are a few cases where infant data was not transferred electronically, and this is captured via verification of infant medical record number, infant name, and/or date of birth. At these instances, the Data Coordinator inputs infant data based on hard copy information. One probable cause for this lack of infant data to be electronically transmitted may be due to the screener at GMHA not inputting hearing screening information in the GMHA database, which resulted in no record for that child to be transmitted. With the ongoing refinement, expansion of the data fields, a transition to the new server, and the addition of a backup server to another facility within the University campus, updates to the Guam ChildLink technical manual is in draft form and will be finalized upon completion of the transition to the new server. Both the in-house Guam ChildLink technical manual and the one by the on-island technical support company has been developed. These two resources will be integrated and disseminated, after review with the Guam EHDI Advisory.

PROGRESSIVE NARRATIVE FOR GOAL 2: The Guam EHDI staff continues to work with DPHSS and GPSS-GEIS to update current MOAs to address data sharing issues and to expand the Guam ChildLink System. One of the activities under this grant period is to expand the Guam ChildLink data system to include data on metabolic screening. Several meetings were held with DPHSS MCH Administrators to discuss the expansion of Guam ChildLink to add the metabolic data fields. In May 2009, Mr. Quansheng Song, Guam EHDI's Off-island Consultant provided technical support to determine how the metabolic screening data fields could be integrated into Guam ChildLink so that data being collected by DPHSS on the 12 associated disorders can continue to be monitored. Linkages with the anticipated Electronic Birth Certificate system were also part of the technical consult discussions with DPHSS. In addition, DPHSS Central and Northern Community Health Centers now are full linked and these centers can access Guam ChildLink. In November 2008, the static IP address for the Guam EHDI server was changed by the local internet provider. All linkages previously established with the Guam EHDI server needed to be renewed with the new IP address. Currently, DPHSS still has a firewall blocking access to the new Guam EHDI server IP address, and work is ongoing with the Information



Technology personnel at DPHSS to address this issue. DPHSS Southern Community Health Center is currently renovating the facility and linkage to Guam ChildLink will commence upon completion of the building renovation. Guam EHD staff continues to meet with GPSS-GEIS to address issues around sharing of data and the confidentiality requirement of the Family Educational Rights and Privacy Act (FERPA) and Health Insurance Portability and Accountability Act (HIPAA). As a result of these meetings, a draft MOA has been completed and is currently being reviewed by GPSS-GEIS and it is anticipated to be signed by June 2009. Meetings were held with the DPHSS-MCHB to review the goals and objectives of the project and to discuss how Guam ChildLink could be expanded to include metabolic screening information and an electronic birth certificate. In August 2008, Guam EHD facilitated a “Power Lunch” teleconference for the purpose of bringing key stakeholders together to talk about the following: 1) an electronic data system including verification of vital events and State and Territorial statistical data sharing; 2) to discuss how Guam ChildLink works; 3) to learn from the NAPHSIS presentation (via teleconference) and discuss opportunities for technical assistance and funding available through agencies such as Homeland Security, Social Security and other sources; 4) to discuss how Guam may move forward in planning an electronic birth and vital statistics system. Those participating in the “Power Lunch” teleconference were the Director and Administrators of DPHSS, the Chief, Bureau of Information Technology (BIT) for the Government of Guam, GMHA Hospital Administrator, Leesa Shem-Tov, NAPHSIS and Guam EHD staff. As a result of this meeting, DPHSS Director stated that he will work with his staff to review the support and technical assistance needed for an electronic birth certificate process and will contact NAPHSIS.

Guam EHD continues to provide information at different levels through the following data reporting cycle as a mechanism for data sharing: 1) Weekly transmission reports of all infants screened prior to discharge at the GMHA to the Guam ChildLink System. 2) Monthly reports are provided to the nursing supervisors at GMHA and the General Manager at Sagua Mañagu Birthing Center of the number of infants screened, number of infants referred for second screening and referral rates of each individual screener. 3) Monthly reports are provided to the GPSS-GEIS Part C Coordinator of all infants with high risk factors that will need to return to GPSS-GEIS for a 6 month re-screen. 4) Quarterly reports are provided to the Guam EHD Advisory Committee of the progress and percent of infants screened, number of infants that return for a 2nd screening, infants referred for a diagnostic audiological evaluation, and for early intervention services. 5) Monthly reports are provided to Association of University Centers on Disabilities National Information and Reporting System indicating the numbers of babies screened and their ethnicities. These reporting cycles have been an effective mechanism for data sharing with partnering agencies.

The Guam EHD staff is working to refine how accurately data on medical home is being collected and reported. Guam ChildLink has in place a data field that tracks an infant’s primary physician and medical home. This information is collected prior to discharge from a birthing facility. However, after file reviews and case analyses, there are instances that the physician identified doesn’t represent the infant’s medical home. For example, an OBGYN physician may be listed as the infant’s attending physician but may not be the infant’s primary care physician or medical home after discharge from the birthing facility. Further training is needed for nurses and

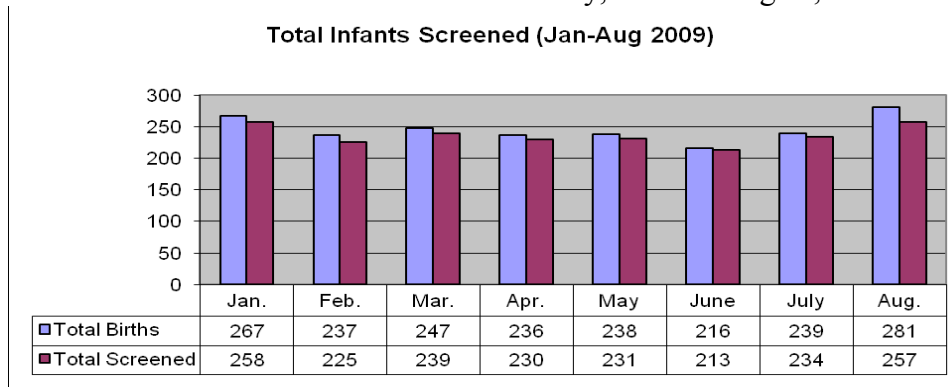


nurses aides to verify that the physician identified is also the infant’s primary care physician or medical home and that information is accurately entered in the database. As noted in Section 1, USNH does not report any data to Guam ChildLink. However, USNH-EDIS are members of the Guam EHDI Advisory Committee and are working to schedule a meeting with the Commanding Officer to discuss potential sharing of data and in the development of a MOA.

Based on meeting with partnering agencies, adjustments have been made to the protocol based on their input. For example, Sagua Mañagu General Manager requested for a specific data report to monitor the progress of infants born at their facility from initial screening to DAE. Another example, as per information requested by DPHSS, the Data Coordinator and off-island consultant recreated a medical home interactive list that allows Guam EHDI to monitor infants with or without a medical home. This information was used in a federal grant application requiring information of the number of children with or without a medical home.

PROGRESS NARRATIVE FOR GOAL 3: Guam continues to monitor the status and progress of every occurrent birth on Guam. Table 2 provides the status of number of births for each month (for the 2 reporting birth sites only) from January to August, 2009 and the number screened. Screening rates continue to be within 96 to 99% of all birth.

Table 2. Total Infants Screened January, 2009 to August, 2009



This data does not include data from USNH. Excellent progress has been made in the activities reflecting a high percent of infants screened.

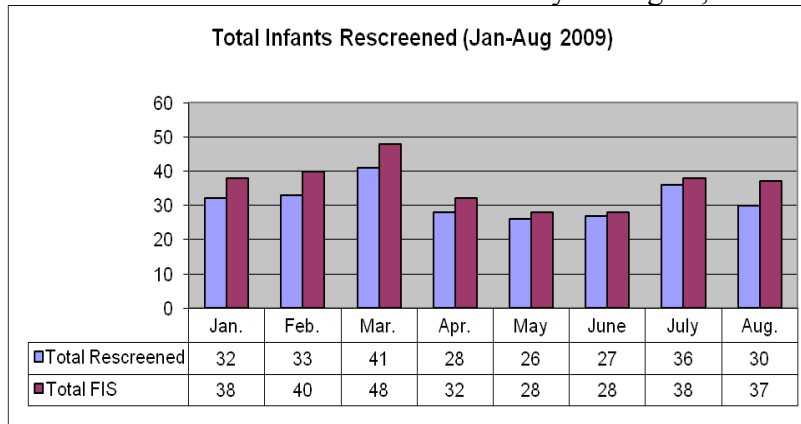
Data is shared at different levels to monitor and track infants’ loss to follow-up. For example, monthly reports are provided to the nursing supervisors at GMHA and the General Manager at Sagua Mañagu Birthing Center of the number of infants screened, number infants referred for second screening and referral rates of each individual screener. This information is also shared at the quarterly EHDI Advisory Committee meetings and discussions are held on recommendations and improvement strategies that could increase the number of infants’ loss to follow from re-screen, completing DAE and accessing early intervention services. When an infant is transferred to GMHA, they are logged into their logbook as an infant transferred from Sagua Mañagu. Hearing screening information is included in the documents given to GMHA upon admission.

In monitoring infants loss to follow up at three levels: (1) lost to follow up re-screening, (2) lost to diagnostic audiological follow up, (3) infants with hearing loss who are lost to follow



up for needing early intervention services, Guam EHDI continues to develop methods for decreasing loss to follow up and monitoring these rates using Guam ChildLink. From January to August, 2009, the number of infants who failed initial screening and returned for a second screening has ranged between 85 to 87%.

Table 3. Total Infants Rescreened January to August, 2009



In conducting a case analysis, for this reporting period there were 49 out of 50 infants or 98% returned for 2nd screen at Sagua Mañagu compared to 121 out of 150 or 81% GMHA infants that return for 2nd screen at the University of Guam- Pediatric Evaluation and Developmental Services (PEDS). Of the infants that failed the 2nd screen, 13 were referred for DAE between July 1, 2008 and August 30, 2009. The status of these infants are provided in Table 4 and show that 9 infants had normal hearing, two infants had parents who refused services, one infant requires further assessment to determine the level of hearing loss and one infant is pending.

Table 4. Status of Infants Referred for DAE July, 2008-August, 2009

Infants N=5	DOB	Date of DAE	Date of IFSP	Total Months from DOB to IFSP
D.P.	7/12/08	7/12/08	Normal Hearing	
S.M.	9/12/08	Parents Refused Services		
M.Y.	9/19/08	Parents Refused Services		
J.P.	9/22/08		Normal Hearing * need to return in 3 to 6 months.	
J.G.	12/1/08	1/22/09	Normal Hearing	
J.P.	1/21/09	2/23/09	Normal Hearing	
J.R.	3/8/09	4/9/09	Normal Hearing	
O.D.	4/21/09	6/5/09	Normal Hearing	
G.S.	6/21/09	7/27/09	Normal Hearing	
K.Y.	7/17/09	8/4/09	Undetermined hearing loss on left ear (no IFSP)	
L.R.	7/22/09	8/25/09	Normal Hearing	
J.S.	7/28/09	8/25/09	Normal Hearing	
E.E.	8/1/09	Sched. For 9/26/09		



Challenges were encountered in having the GPSS-GEIS program report data to Guam ChildLink. GPSS-GEIS made modifications to their database system and relocated to another facility located at the southern part of the island. Due to the lack of DSL internet access and firewall issues, GPSS-GEIS currently is not linked to Guam ChildLink and data reporting has had to return to manual input until GPSS-GEIS is full linked once they are stable in their new location.

Case analysis has shown to be an excellent strategy to find issues or barriers around EHDHI procedures or individual families concerns. A random report was generated from Guam ChildLink and case analysis was conducted by the Project Director of infants in need of DAE. As a result of the review, it was noted that 3 infants were delayed in completing DAE. Further investigation was conducted only to find out that the only Audiologist on Guam that performs DAE for young children was off-island. As a result, intervention from GEHDI expedited the DAE process.

Due to the Project Director's medical leave between February and April, 2009, a more abbreviated report was completed and prepared for dissemination. The annual report for 2008 was integrated into a Guam EHDHI Progress-At-A-Glance and was presented to the Guam EHDHI Advisory Committee for their review and input. The report highlights a parent story and progress made on the goals of the project. It provides a composite review of Guam EHDHI's progress in screening all infants from 2005 to 2008. An official Annual Report for 2008-2009 will be prepared and disseminated for Year 2.

PROGRESS NARRATIVE FOR GOAL 4: Guam EHDHI staff participates in the monthly national teleconference calls. Because of the time difference, team members alternate attending. Other activities under this goal includes survey completion. Guam submitted the national survey from the National Center of Birth Defects and Developmental Disabilities EHDHI for 2007. In addition, the Guam EHDHI staff participated in two teleconferences in October and November 2008 with other Pacific EHDHI Jurisdictions, CDC, HRSA & NCHAM to the discuss a Pacific Island Regional EHDHI meeting that was held in Dallas, Texas in March 2009. The Guam EHDHI staff participates in the continues to participate in the monthly national CDC teleconferences.

The Guam EHDHI website (www.guamehdi.org) is updated on a quarterly basis or as needed. The Guam EHDHI website provides the following data information: 1) a graph charting data trend on the percent of infants failing initial screen, percent of infants returning for 2nd screen, and percent of high risk infants returning for 6th month re-screen; 2) provides a yearly percentage of infant screen prior to discharge at GMHA and Sagua Mañagu Birthing Center; and 3) an annual chart of infants receiving DAE before 3 months of age. In addition, developed products and research presentations conducted by Guam EHDHI staff over the course of the project is available for review. The Guam EHDHI website also provides links to related website that provide information on infant hearing. The Guam EHDHI website was redesigned to ensure it is accessible and user friendly for all users of the sites especially parents. Focus groups of parents and service providers will be conducted to determine user friendliness and ease in accessing the newly redesigned Guam EHDHI website. The Guam EHDHI Advisory Committee is provided with quarterly data at each advisory meeting and this provides an opportunity for input to improvement strategies and recommendations. In addition, Guam EHDHI shared performance data on the goals of the EHDHI project at the Pacific Island Meeting held in Dallas, Texas.



A Pacific Regional meeting was held at the Annual EHDI Conference held in Dallas, Texas in March 2009. The Guam Team developed an initial agenda for the meeting and “Save the Date Flyer” for the Pacific EHDI meeting. Draft agenda was further refined during Guam’s site visit in September. During the Pacific meeting, regional data issues and implementation strategies were discussed. Currently, the Commonwealth of the Northern Marianas (CNMI) has a database similar to Guam ChildLink. The Federated States of Micronesia (FSM) and the Republic of Palau (ROP) are considering aligning their respective data tracking and surveillance systems with Guam ChildLink. This alignment would ease in the process of linking data systems within the region. American Samoa is currently creating their data system, and is incorporating fields collected by Guam ChildLink in their system.

PROGRESS NARRATIVE FOR GOAL 5: To identify late onset or progressive hearing loss, the Guam EHDI staff reviewed all children receiving special education services for hearing loss and cross compared this list with Guam ChildLink data. Through this process, 4 children were receiving services for hearing loss, but were not identified by the Guam EHDI Project, 2 of these children screened normal and were later found to have late onset of hearing loss. To determine how Guam ChildLink can expand data fields to capture relevant information that will assist with the early identification of late onset or progressive hearing loss, and to develop guidelines for tracking and monitoring this type of hearing loss, further case study is needed from existing cases to determine when families became aware of the type and severity of the hearing loss, what measures were taken, and how quickly services were provided. There are no infants found to have late onset of hearing loss for this reporting period. However, quarterly case analysis will continue for monitoring and modification to the data fields will be made as needed. By the end of Year 1 the first draft of the Guam ChildLink Quality Assurance Plan was completed. In Year 2, further refinements of the QA plan will continue to insure the development of a long term quality assurance plan for Guam ChildLink.

SECTION 3: Program Evaluation Narrative

An evaluation question was posed for each of the 5 grant goals, with corresponding objectives listing evaluation criteria for determining evidence of completion. For Goal 1, the evaluation question posed was “*How did Guam EHDI enhance and improve methods to accurately identify, match, and collect unduplicated individual, identifiable data and secure web reporting?*” Guam EHDI provided a 2008 data file analyses report, a list of Guam ChildLink modifications made, it conducted test run files and the off-island technical consultants trip report provides evidence of this consult for system improvement, an updated technical manual is available for review and all technical difficulties with Guam ChildLink were resolved with no interruption in data flow over the reporting period. For Goal 2, the evaluation question, is “*How did Guam EHDI collaborate with other reporting sources to develop reporting protocols for all involved agencies? Did Guam EHDI increase data sharing, integration, and linkage?*” Agenda and meeting minutes provide evidence of continued collaborative agency meetings with all stakeholders. New electronic linkages are in place with DPHSS Central and Northern Community Health Centers are now linked into the Guam ChildLink system. MOAs are currently being updated to include Guam ChildLink data reporting by birth sites, clinics, and early intervention. Protocols for



Guam ChildLink electronic linkages are now documented in technical manuals and the Project Coordinator will be completing revisions on reporting protocols when 2-step AABR screening is put into place.

For Goal 3, the evaluation question is, *“How did Guam EHDI continue to monitor the status and progress of every occurrent birth on Guam?”* Guam ChildLink has produced quarterly reports that are presented to the Guam Advisory Committee which reports on every occurrent birth and follow up for those infants referred. While there is a methodology in place to locate and screen infants with no initial screening results, 95% or more of all infants born at the 2 main birthing sites on Guam were screened and only NICU infants or those who passed away or moved away immediately after birth may have not been screened, but these are closely monitored. Cases analyses reports on infants lost to follow up continues to be monitored, improvements were observed in the number of infants returning for 2nd screening. A total of 41 lost to follow strategies for reducing lost to follow up in all categories were generated this year and are now being evaluated for inclusion in the Guam ChildLink system. A draft copy of the Guam EHDI Progress-at-a-Glance is ready for distribution which gives an overview of data from 2005 to 2008 and provides stories and information on families with young with hearing loss who were identified through the Guam EHDI program. This brochure will be disseminated at the next Advisory meeting and posted on the Guam EHDI webpage. For Goal 4, the evaluation question is, *“How will Guam EHDI report standardized aggregated hearing screening information, including ear specific diagnosis, maternal demographics, date of diagnosis, and information on early intervention service data?”* Meeting minutes from Guam EHDI staff meetings document participation in national teleconference meetings which assist with reporting requirements. The Guam EHDI webpage was completely revised and evidence is available directly on line, trend analyses of Guam ChildLink data has shown to be very useful in locating infants with hearing loss and often associated with other disabling conditions such as cleft lip/palate and Down’s Syndrome. Guam EHDI continues to collect consistent data on screening, rescreening, diagnosis, and early intervention with continued plans to improve data collection to include maternal demographics (which Guam ChildLink is already prepared to collect) and ear specific data that is more refined for diagnosis and intervention. For Goal 5, the evaluation question is *“How did Guam EHDI improve and enhance identification and collection of standardized data on infants and children with late onset or progressive hearing loss? Did Guam EHDI develop an analytic plan to address loss to follow up rates? Did Guam EHDI develop a quality assurance and improvement plan based on information learned during the implementation of activities during the grant cycle”* Guam EHDI has developed a plan for matching data with DPHSS metabolic screening and investigating immunizations database system for possible linkage. With the anticipated technical support from NAPHSIS and site visit scheduled for November, improvements are expected as Guam moves to an Electronic Birth Certificate system. Guam EHDI has identified children with late onset and will do further analyses of these cases to determine how to identify these children earlier. An analytic plan to address loss to follow up is still in process as meetings with the birth sites and early intervention continue into Year 2. A working draft of the Guam ChildLink Quality Assurance Plan was completed and is now undergoing review and revision. Guam EHDI completed Year 1 having made significant progress in all goals and objectives. Activities were completed, despite set back outlined in the Interim report and it is anticipated that Year 2 will continue to show excellent progress.



ATTACHMENT 1.

Guam EHDI

Tracking, Surveillance and Integration-System Enhancement and Refinement
2008 Data File Analyses of Infants Identified with Hearing Loss

GOAL #1-Objective 1.1 Enhance Guam ChildLink through the expansion of data fields relevant to the needs for Guam, by conducting data file analysis of all infants identified with hearing loss to determine if infants were identified and provided services within appropriate timelines and to identify gaps in service.
Activity 1.1.1. Project Coordinator & Data Coordinator will extract and analyze all cases of infants born in 2008 identified with a hearing loss. Activity 1.1.2 Based on the data file analysis results, Guam EHDI will enhance and improve Guam ChildLink by making the necessary technical modifications needed.

GEHDI #	Ethnicity	Gender	Infant screened w/in 1 month?	Infant received DAE w/in 6 months?	Infant has IFSP w/in 6 months?	Left Ear	Right Ear	Other Disability Conditions or Notations
25901	Palauan	Female	Yes	Yes	Yes	Normal	Moderate Sensorineural	None
26082	Filipino	Female	Yes	Yes	Yes	Mild Conductive	Mild Conductive	Has cleft palate
26445	Chamoru	Male	Yes	Yes	Yes	Mild Conductive	Normal	Has bilateral cleft lip and palate
26627	Filipino	Male	Yes	Yes	Yes	Moderate sensorineural	Undertermined may be moderate sensorineural	Head and neck deformity-both ears are malformed
26639	Filipino	Female	Yes	Yes	Yes	Mild sensorineural	Normal	None
26948	Chamoru	Male	Yes	Yes	Yes	Mild sensorineural	Normal	Infant has family history of hearing loss
27201	Filipino	Male	Yes	Yes	Yes	Moderate conductive	Moderate conductive loss	Infant has Downs Syndrome
27458	Chuukese/ Multieth	Male	Yes	Yes	Yes	Mild conductive	Normal	None
27513	Chamoru	Male	Yes	Yes	Yes	Mild conductive	Normal	Has risk factors
281717	Chuukese	Male	Yes	Yes	Yes	Mild conductive	Mild conductive	Has bilateral cleft lip and palate



Summary

The total number of infants born in 2008 and captured by Guam ChildLink was 3,018 with 2,996 or 99% receiving a hearing screening prior to 1 month of age or prior to hospital discharge. The total number of infants referred for further diagnostic audiological evaluations (DAE) was 20 or less than 1% of the total number of infants screened in 2008.

From the group referred for DAEs, 10 infants were found to have a hearing loss. The ethnic breakdown of infants with hearing loss showed Filipino infants having the highest incidence with 40%, followed by Chamoru infants who represented 30% of the group and Micronesian infants (Palauan and Chuukese) also with 30% incidence of hearing loss in 2008. Gender distribution showed, males dominated the group of infants found with hearing loss, with 70% being males, while females represented 30% of the group.

All infants found to have hearing loss were screened, rescreened, given a DAE and placed in Early Intervention within the 1-3-6 time limits. In analyzing the type of hearing loss found, 70% have mild conductive hearing losses in either one or both ears and 30% have moderate sensorineural losses in either one or both ears. Three infants born late in the year are still pending a DAE at this writing.

The most significant findings has been the number of infants identified with hearing loss who had other associated disabling conditions, 70% of the group had other conditions, with 30% having either cleft lip, cleft palate, or both

Implications for Guam ChildLink:

1. There is a need to add into the DAE file a drop down menu which includes the 14 official Special Education disability categories so that infants found to have hearing loss with other associated disability conditions can be identified. At present, the Data Entry Clerk enters the other disability condition in the open narrative sections on either the Demographic or Rescreening file. There is no way to summarize the number of infants who have other disabling conditions or the type of disability, without looking at each individual file and tediously reading each narrative entry from any one of the files. In 2008, the number of infants found to have cleft lip and palate was significant, the implications for training for early interventionists to support IFSPs for these infants may be necessary.
2. The risk factor list continues to be problematic as the categories are too general, e.g. "syndrome" can mean a variety of high risk factors associated with a wide range of syndromes. Further refinement is needed in the high risk factors listing.

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