



Project Area: GUAM, U.S. Territory
Award Number: DD08-803, Early Haring Detection and Intervention (EHDI)
Tracking, Surveillance, and Integration
Name of Persons completing this report: Dr. Heidi San Nicolas, Principal Investigator, Elaine Eclavea – Project Coordinator, Joseph Mendiola- Data Coordinator, Elizabeth Borja- EHDI Media Developer, and Vicky Ritter- EHDI Hearing Screener
Email Address: heidi.sannicolas@guamcedders.org
Phone Number: (671) 735-2480

PROJECT NARRATIVE

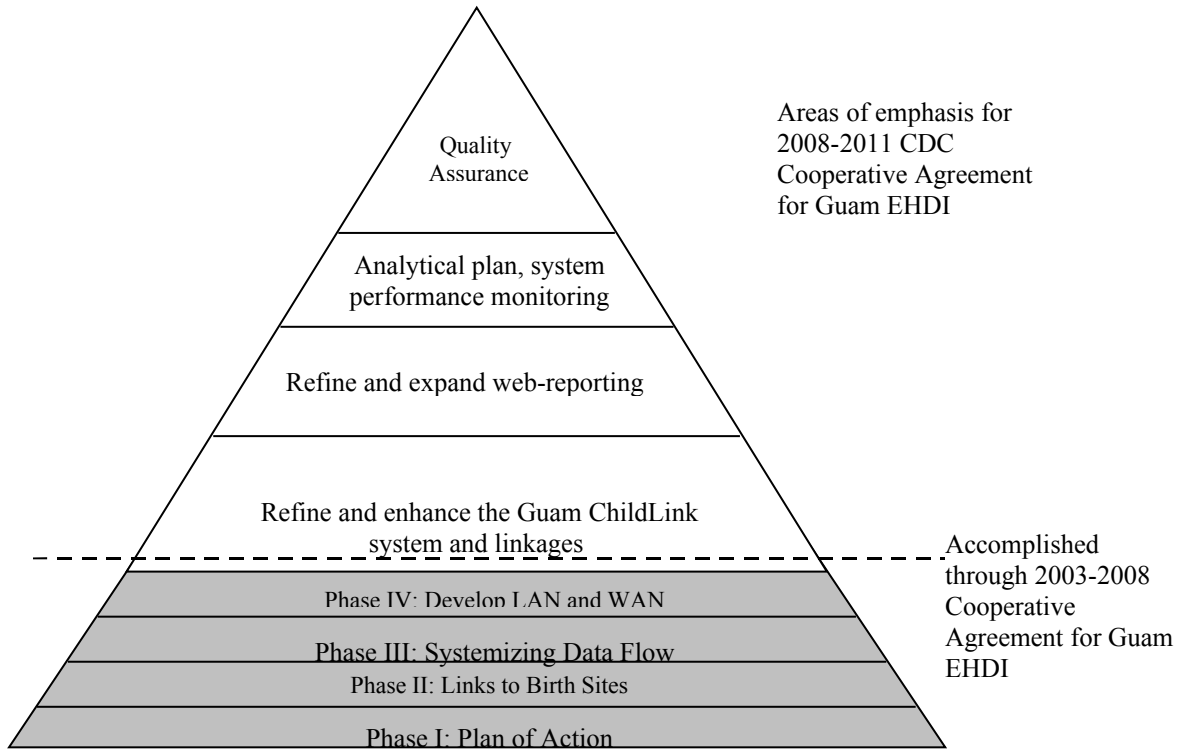
I. CURRENT BUDGET PERIOD PROGRESS

Section 1: Background

The purpose of the Guam Early Hearing Detection and Intervention (Guam EHDI) project is to track and monitor all infants born on Guam to ensure they receive a hearing screening test prior to being discharged from a birthing facility or within the first month of life. Infants that fail the hearing screening are referred for a full diagnostic audiological evaluation (DAE) and early intervention services, and are linked to a medical home and parent-to-parent support group. 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).

As noted in Figure 1, a pyramid is used to depict the conceptual model for the development of the Guam EHDI Tracking and Surveillance system. The base of the pyramid indicates the planning that occurred from 2003-2008 to the development of a quality assurance system at the top. The unshaded areas reflect new directions under this current grant application.

Figure 1: Conceptual Model of Guam ChildLink Development



Guam ChildLink continues to collect initial and follow-up hearing screening data from the GMHA and Sagua Mañagu Birthing Center. Data on infants found with potential hearing loss are tracked and monitored to ensure timely DAE and referral to the early intervention program. Currently, the Guam EHD Project does not receive or report any data from the U.S. Naval Hospital (USNH). A major focus of this grant cycle continues to be on data management to support the following: 1) Ensuring no duplication of data occur 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 interim report will describe the progress of the Guam EHDI program goals, objectives, and activities between July 1, 2008 to December 31, 2008. A narrative scale of met, in progress, or unmet is provided for each project goal, followed by a description of progress made, and status of all objectives and activities relevant to Year 1.

Section 2: Goals, Objectives, and Activities

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 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 services.

PROGRESS:

Guam is in progress with this objective. The accuracy of the data in Guam ChildLink continues to be monitored through the implementation of 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 that were electronically transmitted into Guam ChildLink. 3) If there are discrepancies with the data, the Data Coordinator will review 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 firewalls in place before gaining access into the Guam EHDI server.



Activity 1.1.1. The Project Coordinator and Data Coordinator will extract and analyze all cases of infants born in 2008, identified with hearing loss in 2008.

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.

Activity Updates:

Progress continues to be made on Activities 1.1.1 and 1.1.2. 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, a user specific report was created for Sagua Mañagu to monitor aggregate data of infants from initial screening to diagnostic audiological evaluation (DAE).

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.

PROGRESS:

There are 3 birthing sites on Guam: 1) GMHA, civilian hospital; 2) Sagua Mañagu Birthing Center; and 3) U.S. Naval Hospital (USNH) military hospital. 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.

Activity 1.2.1. The off-island consultant working with the Data Coordinator will conduct test runs to troubleshoot the electronic linkages and security systems between all sites and Guam ChildLink.

Activity 1.2.2. Using the information from the test runs, the off-island consultant and the Data Coordinator will resolve any technical difficulties or issues uncovered to improve information accuracy, ensure no duplication, and to continue system upgrades.

Activity Updates:

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.

OBJECTIVE 1.3: By the end of Year 1, review and revise the Guam ChildLink technical manual in collaboration with all stakeholders.

PROGRESS:

Guam is in progress with this objective. 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.

Activity 1.3.1. Local technical consultant in collaboration with Guam EHDI staff will review and revise the Guam ChildLink technical manual and ensure the manual reflects security systems in place, including how the system ensures all technical modifications meet HIPPA and FERPA requirements.

Activity 1.3.2. The Project Director will insure that all sites electronically linked to Guam ChildLink, are given a copy of the developed technical manual.

Activity Updates:

Progress continues to be made on Activities 1.3.1 and 1.3.2. The Guam EHDI staff are familiar with the requirements of HIPPA and FERPA and are working on updating the draft manual to ensure all technical modifications needed are documented in the manual. The Data Coordinator provides training and support at least twice a month at the Sagua Mañagu Birthing Center. For GPSS-GEIS, training and support was provided to the GPSS-GEIS data clerk in establishing linkage with the Guam EHDI server. Copies of the Guam ChildLink user manual are provided as part of the training.

Status of the GOAL 1:

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| MET | IN PROGRESS | UNMET |
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GOAL 2: Guam EHDI will collaborate with reporting sources to develop Guam EHDI 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. Guam EHDI is also collaborating with the National Association for Public Health Statistics and Information System (NAPHSIS) to support DPHSS



effort to move to an electronic birth certificate system and to explore the possibility of using a new linkage system called the State and Territory Exchange of Vital Events (STEVE) which will improve relevant data sharing integration and linkage.

PROGRESS:

Guam is in progress with this objective. The Guam EHDI staff is working with DPHSS and GPSS-GEIS to update the MOA 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, will be on island to provide technical support in developing the metabolic data sets that align with the 12 disorders that DPHSS is currently collecting. In addition, DPHSS Central and Northern Community Health Centers currently have a computer system that provides them access to 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 EHDI 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.



Activity 2.1.1. The Project Director and Coordinator will conduct bi-monthly meetings with the relevant agencies to continue collaborative discussions and determine the feasibility of data interface with the agency's database (reporting source). Guam EHDI will facilitate and support DPHSS's effort to move to an electronic birth certificate system with technical support from NAPHSIS.

Activity 2.1.3. Amend existing MOAs to reflect other data sharing linkages or develop new MOAs with agencies where linkages are to be established.

Activity Updates:

Progress continues to be made on these activities. Three 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 EHDI 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 EHDI 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.

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.



PROGRESS:

Guam continues to make progress on this objective. Guam EHDI 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 EHDI 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 EHDI 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.

Activity 2.2.1. The Project Director, Coordinator, and Data Coordinator in collaboration with other partner agencies will develop protocols to support data sharing integration and linkages.

Activity 2.2.2. The Project Coordinator will meet with agency staff involved with EhDI activities and conduct interviews on the implementation and effectiveness of the protocols and make adjustments as needed.

Activity Updates:

Progress continues to be made on these activities. 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.

Status of the GOAL 2:

| | | |
|-----|--------------------|-------|
| MET | IN PROGRESS | UNMET |
|-----|--------------------|-------|

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.

PROGRESS:

Guam continues to make progress on this objective. Guam EhDI provides the following data reports on all infants screened prior to discharge from a birthing facility: 1) Weekly transmission reports of all infants screened prior to discharge at the GMHA to the Guam



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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 infants referred for second screen and referral rates of each individual screener. However, further expansion is needed to add a “Flag” if the baby has a record and no hearing results. Guam’s off-island consultant will be working closely with the Administrator at GMHA and Guam EDHI Data Coordinator to add this feature to the data base.

For this reporting period, there were 1606 births between July and December 2008. Of the 1606 births, 1579 or 98% were screened prior to discharge at GMHA and at Sagua Mañagu.

Table 1: Initial Hearing Screening Results

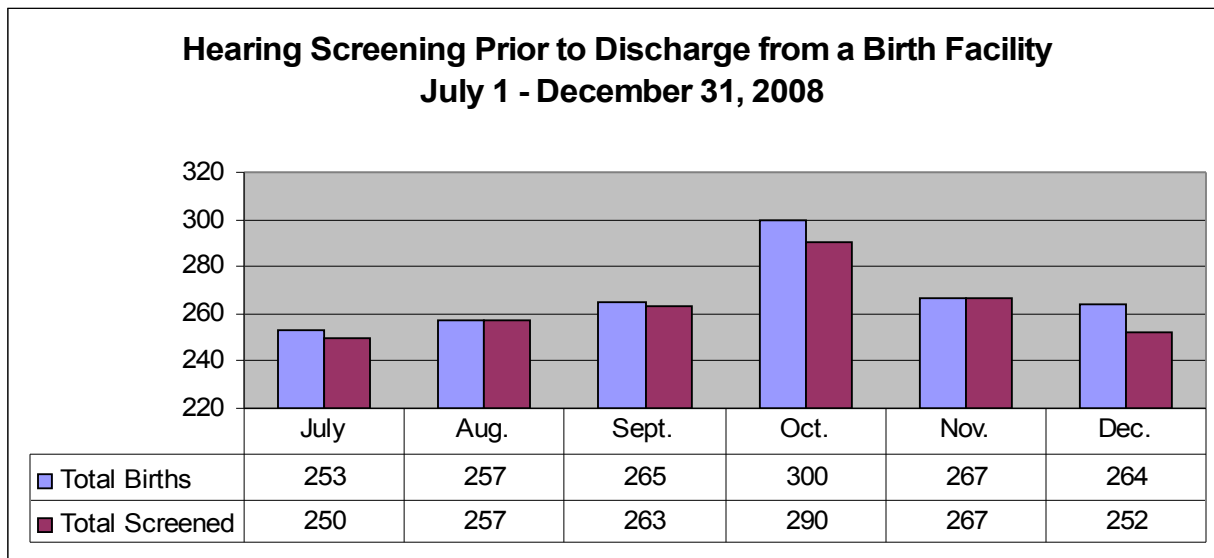


Table 1 indicates the number of infants screened between July and December 2008. For the months of August and November the hearing screening was at 100%. This data does not include data from USNH. Excellent progress has been made in the activities reflecting a high percent of infants screened.

Activity 3.1.1. Guam EHDI staff will continue to compare, report, and disseminate to the Guam community, the number of infants born on Guam to the number of infants screened prior to discharge or within 1 month of age, with the continued goal of achieving 100% screening and to



provide solutions to any needs or issues which may arise in the routine hearing screening at the birth sites, i.e. turnover of nursing staff, equipment breakdown, back-up equipment needs, training needs, electronic transfer difficulties, etc.

Activity 3.1.2. Infants who may not have been given a hearing screening test prior to discharge due to complicating medical or other factors will automatically be electronically flagged at Sagua Mañagu by the Guam ChildLink system and case-specific, individualized follow-up will be initiated by the Hearing Screening Technician to locate the infant/family either through the medical home or birth site, to insure that the infant receives an initial hearing screening test prior to 1 month of age.

Activity 3.1.3. Mothers who go to the Sagua Mañagu Birthing Center who later develop complications during delivery or give birth to infants found to have complicated medical issues after birth are transferred to GMHA. Sometimes hearing screening testing is not completed at either birth site as a result of the transfer. The Hearing Screening Technician will ensure that all infants transferred are given a hearing screening test.

Activity Updates:

Progress on these activities are ongoing. 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 EHDII 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.

OBJECTIVE 3.2: While methodologies for decreasing loss to follow up at all levels continue, Guam EHDII 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

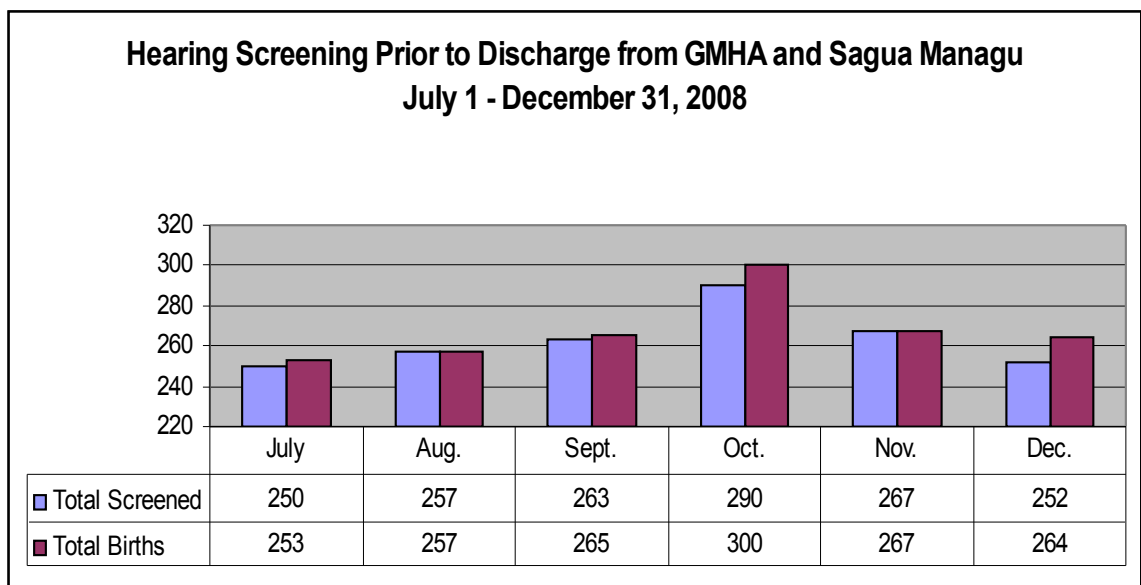


loss and not receiving early intervention services to determine gaps in service; and (4) Infants with hearing loss and receiving early intervention services to determine gaps in follow-up medical or audiometric services.

PROGRESS:

Guam continues to closely monitor the progress of this objective. As noted in Table 2, there were a total of 200 infants that failed initial screening during this timeframe and of those 200 infants, 170, or 85% returned for a second screen. Table 2 below shows that 30 infants, or 15%, were lost to follow up.

Table 2: Infants Return for Rescreen



Guam EHDI works closely with the birthing facility to schedule appointments for 2nd hearing screening before the infant is discharged. 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, 5 were referred for DAE between July and December 2008. As indicated in Table 3, 3 of the 5 had normal hearing, 2 parents refused DAE.



Table 3:

| 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 | |

Recently, data from GPSS-GEIS has not been entered into Guam ChildLink because GPSS-GEIS had modifications to their database system and have recently 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.

Activity 3.2.1. Each quarter, the Project Director and Project Coordinator will randomly select cases from each of the four categories listed above and conduct a case analyses, retracing efforts made to locate infants lost to follow-up in all categories to identify system breakdown issues and generate appropriate family-friendly, culturally relevant, resolutions to decrease lost to follow up in all categories.

Activity Updates:

Progress on this activity is continuous. Case analysis is an excellent strategy to find issues or barriers around EHDI procedures or individual families concerns. For example, 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.

OBJECTIVE 3.3: Publish and disseminate an annual report of Guam ChildLink which gives both aggregate and anonymous case specific information to key stakeholders including policy



makers, agency Directors Health Care professionals, and other community involved decision makers.

PROGRESS:

Guam is in progress with this objective. A draft annual report at-a-glance for 2008 was presented to the Guam EHDII Advisory Committee for their review and input. The report highlights a parent story and progress made on the goals of the project. The final 2008 Guam EHDII Annual Report At-A-Glance will be published and disseminated to parents, Guam EHDII Advisory members, policy makers, and agency partners by June 2009.

Activity 3.3.1. Work with the Guam EHDII Advisory Committee during the first quarter of each year, review preliminary drafts of the annual report to be developed by the Project Director and Coordinator using Guam ChildLink. Use feedback from the committee to determine areas that need to be included, strengthened, deleted or revised.

Activity 3.3.2. By the end of the 2nd quarter of each year, work with Guam CEDDERS publication staff to finalize a camera-ready draft of the annual report for dissemination.

Activity 3.3.3. Develop and maintain a listing of all relevant individuals/agencies (both on-island and off-island) who will receive hard copies of the annual report and disseminate the publication in the 3rd quarter of each year.

Activity 3.3.4. Each year develop and analyze a feedback survey to be inserted as part of the annual report and encourage individual/agency to complete the survey and return it to Guam EHDII via fax, on-line feedback, or mail back. Complete survey analyses and review feedback with the Advisory Committee to determine areas in need of improvement.

Activity Updates:

Progress on these activities are on target. The publication of the 2008 Annual Report will be disseminated to all partnering agencies and the EHDII Advisory members. A survey will be conducted 1 month after the dissemination of the report to gather feedback and input on the report.



Status of the GOAL 3:

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| MET | IN PROGRESS | UNMET |
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GOAL 4: Guam EHD 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 EHD will continue to participate in monthly National teleconference meetings to stay current in any new or modified CDC reporting requirements.

PROGRESS:

Guam is in progress with this objective. The Guam EHD staff participates in the monthly national calls. Guam submitted the survey from the National Center of Birth Defects and Developmental Disabilities EHD for 2007. In addition, the Guam EHD staff participated in two teleconferences in October and November 2008 with other Pacific EHD Jurisdictions, CDC, HRSA & NCHAM to discuss a Pacific Island Regional EHD meeting that was held in Dallas, Texas in March 2009.

Activity 4.1.1. The Project Director and/or Project Coordinator will participate in the monthly CDC teleconference calls to continue participation in the national effort to improve and develop a national EHD reporting system.

Activity Updates:

Progress continues on this activity. The Guam EHD staff participates in the monthly national calls.

OBJECTIVE 4.2: Each year review and increase options for the community and region to access relevant Guam EHD resources, data, and materials, especially the DPHSS MCH Children with Special Health Care Needs Coordinators through the Guam EHD website.

PROGRESS:



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Guam is in progress with this objective. The Guam EHDI website (www.guamehdi.org) is updated on a quarterly basis or as needed. The Guam EHDI 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 EHDI staff over the course of the project is available for review. The Guam EHDI website also provides links to related website that provide information on infant hearing.

Activity 4.2.1. The Guam EHDI staff will upgrade web reporting procedures so the Guam EHDI website will be more user-friendly for parents, accessible to the community, and provides updated information and options for interactive exchange between families and all levels of professionals who make routine or periodic contact with the family.

Activity 4.2.2. Options for increased community participation and access will also occur through the dissemination of Annual Report, Briefs, and Fact Sheets.

Activity 4.2.3. Develop worksheets which present new inquiries and allow input from stakeholders to observe trend analyses of aggregate data, e.g. displaying data in new ways so the Guam EHDI Advisory Committee can make comparisons with national incidence of hearing loss within appropriate confidence levels and degree of freedom for meaningful trend analyses.

Activity 4.2.4. Conduct a Pacific regional meeting to include Guam, Commonwealth of the Northern Mariana Islands, Republic of Palau, Federated States of Micronesia, Republic of the Marshall Islands, and American Samoa to begin discussions for regional collaboration of all Pacific EHDI programs to review resource sharing, data sharing options, and other issues and concerns specific to the region.

Activity Updates:

Progress have been made on these activities. The Guam EHDI website will be redesigned to ensure it is accessible and user friendly for all users of the sites especially parents. The Guam



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EHDI staff is using the “Research-Based Web Design & Usability Guidelines” to ensure accessibility. It is anticipated that the launch of the new website will be in July 2009.

On a quarterly basis, the ChildLink data on the goals of the Project is reported to the Guam EHDI Advisory Committee in which they provide input to improvement strategies and recommendations. In addition, Guam EHDI shared performance data on the goals of the EHDI 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. Planning for the meeting took place through face to face meetings, telephone calls, and teleconference calls facilitated by CDC. 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.

Status of the GOAL 4:

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| MET | IN PROGRESS | UNMET |
|-----|--------------------|-------|

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: In Year 1, develop a plan to identify infants tested that passed hearing screening prior to discharge and later found to have a hearing loss at 3 or 4 years of age by



matching Guam ChildLink data with GPSS Child Find data, GEIS data, or through the Guam EHDI Parent-to-Parent Support Group.

PROGRESS:

Guam is in progress with this objective. There were 2 children identified with late-onset hearing loss for this reporting period.

Activity 5.1.1. In the first quarter of Year 1 conduct meetings with GPSS-Child Find, GPSS-GEIS, and Family-Support Group to develop a sequential plan and process to match infants who passed hearing screening and later emerged as preschoolers with hearing loss. By the end of Year 1 a list of children found to have late onset or progressive hearing loss will be developed, analyzed and a discussion initiated for earlier detection.

Activity Updates:

The Guam EHDI staff conducted a case analysis of children 3 to 4 years old that were identified with hearing loss and enrolled in GPSS Special Education Program but were not identified by the Guam EHDI Project. As a result of the case analysis, there were 2 children found to have late onset hearing loss. Further discussion is needed to expand the data fields in Guam ChildLink to capture this data and to develop guidelines for tracking and monitoring these children with GPSS Special Education Program.

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.

PROGRESS:



Guam is in progress with this objective. There are no infants found to have late onset of hearing loss for this reporting period. However, quarterly case analysis will continue as a form of monitoring and modification to the data fields will be made as needed.

Status of the GOAL 5:

| | | |
|-----|--------------------|-------|
| MET | IN PROGRESS | UNMET |
|-----|--------------------|-------|

SECTION 3: Barriers and Resolutions

Guam EHDI has identified the following barriers and strategies for resolving these issues: 1) Lack of data sharing of USNH in Guam ChildLink. As noted earlier, USNH EDIS staff are members of the Guam EHDI Advisory Committee and are working with the administrative staff of the new Commanding Officer to schedule a meeting to discuss participation in Guam ChildLink. It is anticipated that this meeting will be scheduled in June 2009. 2) Lack of electronic birth certificate is a continuous challenge. Guam EHDI facilitated several teleconference calls with Leesa Shem-Tov, Re-engineering Project Manager from the NAPHSIS to discuss potential strategies in moving towards an electronic birth certificate. 3) There are several instances that infants were not screened prior to discharge at GMHA. The strategy to address this issue is to work with the Health Information and Technology Administrator to add “red flags” in the hearing screening data sheet that will identify infants that hearing screening was either not completed or the hearing screening results were not inputted into the Guam ChildLink. 4) In October 2008, GPSS-GEIS had stopped sharing hearing screening data of infants with high risk that returned for a 6 month follow-up due to issues around confidentiality and FERPA requirements. After several meetings and discussion on the FERPA requirements, an updated MOA was developed that addressed this issue. Since the Guam EHDI project is a “participating agency” of GPSS-GEIS and provides more than child find activities then this hearing data information can be shared. This is documented in the MOA that will be signed by May 2009. 5) After case analyses, inconsistent data on infants’ medical home was noted in several records. To address this issue, training was scheduled with the nurses and nurses’ aides at GMHA to ensure that they input the name of the child’s primary care physician and ask the family if this is the child’s medical home. 6) DPHSS Community Health Centers having access



to Guam ChildLink because of firewall issues with DPHSS Community Health Clinics. In November 2008, DPHSS Community Health Centers had their linkages with the Guam EHDI server interrupted due to a server IP address change. The new Guam EHDI IP address is firewalled on the DPHSS network, which prevents a connection via a virtual private network. The Guam EHDI Data Coordinator has been in contact with Information Technology (IT) staff at DPHSS regarding this issue, but progress on this has been stalled. A meeting with the new IT Manager for DPHSS has been scheduled to resolve this issue. 7) In February 2009, GEIS relocated their offices. At their current location, GEIS does not have a steady internet connection. The GPSS-GEIS Program Coordinator is working with the Government of Guam Department of Administration to provide the agency with internet access. Efforts to re-establish linkage with the GEIS server and the Guam EHDI server continues. 8) Capturing late onset data. Currently, Guam ChildLink does not have an explicit way of tracking late onset hearing loss data. Additional fields will be added to Guam ChildLink so that when linkage with the GEIS server is re-established, late onset data will be readily available.

II. NEW BUDGET PERIOD PROPOSED OBJECTIVES AND ACTIVITIES

The following are YEAR 2 proposed objectives, performance measures, activities, and timelines for accomplishing the activities for this upcoming budget period:

(Note: Activity 1.1.1 was for Year 1, activities 1.3.1 and 5.1.2 are for Years 1 and 3, activities 5.3.2 and 5.3.3 are to commence in Year 2, and the remaining activities are ongoing and are referenced in Section 2: Goals, Objectives, and Activities)

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 services. *Performance measures:* List of Guam ChildLink modifications report from data file analyses. Activity 1.1.2 is ongoing thorough Year 2.

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. *Performance Measure:* Copies of test run files and off-island consultant's report; Off-island consultant's report of resolutions to technical difficulties and issues found from test runs. Activities 1.2.1 and 1.2.2 are ongoing thorough Year 2.

OBJECTIVE 1.3: By the end of Year 1, review and revise the Guam ChildLink technical manual in collaboration with all stakeholders. *Performance measures:* Acknowledgement of receipt of technical manual by all relevant sites on file with Guam EHDI. Activity 1.3.2 is to be completed 1st quarter, Year 2.

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. Guam EHDI is also collaborating with the National Association for Public Health Statistics and Information System (NAPHSIS) to support DPHSS's effort to move to an electronic birth certificate system and to explore the possibility of using a new linkage system called the State and Territory Exchange of Vital Events (STEVE) which will improve relevant data sharing integration and linkage. *Performance Measures:* Agenda and Meeting Minutes from each meeting; Plan for Electronic Linkage between Guam EHDI-ChildLink and the reporting source; Amended and new MOAs with relevant agencies. Activities 2.1.1, 2.1.2, and 2.1.3 are ongoing and are updated as needed.

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. *Performance Measures:* Developed protocols with partner agencies on file and disseminated; Project Coordinator's Interview reports and revised protocols where adjustments have be completed. Activities 2.2.1 and 2.2.2 are updates as needed thorough Year 2.

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. *Performance measures:* Guam ChildLink bi-monthly reports indicating births on Guam and



status of hearing screening by birth site; Report by Guam ChildLink on number of infants flagged who did not have an initial hearing screening completed; Hearing Technician's Report of infants transferred to GMHA. Activities 3.1.1, 3.1.2, and 3.1.3 are ongoing.

OBJECTIVE 3.2: While methodologies for decreasing loss to follow up at all levels continue, Guam EHD 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. *Performance Measures:* Case analyses reports, decrease in the number of infants reported as lost to follow up in all categories. List of alternative strategies for lost to follow up infants, based on what works in the Pacific and aligned with recommended strategies by HRSA. Activity 3.2.1 is ongoing through Year 2.

OBJECTIVE 3.3: Publish and disseminate an annual report of Guam ChildLink which gives both aggregate and anonymous case specific information to key stakeholders including policy makers, agency Directors Health Care professionals, and other community involved decision makers. *Performance Measures:* Meeting Minutes from Guam EHD Advisory and a draft copy of the annual report; Final draft of the annual report is ready for dissemination and uploaded to the Guam EHD web site; Dissemination listing of individuals/agencies; Feedback survey, data analyses of surveys, and meeting minutes from the Advisory Committee documenting feedback to be incorporated into the next annual report. Activities 3.3.3 and 3.3.4 are ongoing through Year 2.

OBJECTIVE 4.1: Guam EHD will continue to participate in monthly National teleconference meetings to stay current in any new or modified CDC reporting requirements. *Performance Measures:* Meeting minutes from Guam EHD staff meetings which document feedback reports and sharing with the staff from the national teleconferences; Listing of new data fields or reports available through Guam ChildLink. Activities 4.1.1 and 4.1.2 are as needed through Year 2.

OBJECTIVE 4.2: Each year review and increase options for the community and region to access relevant Guam EHD resources, data, and materials, especially the DPHSS MCH Children with Special Health Care Needs Coordinators through the Guam EHD website.



Performance Measures: Guam EHD website is modified and evidence of specific changes reflected; Log sheet of dissemination of Guam EHD publications; Worksheets developed to facilitate group review and trend analyses; Pacific EHD meeting agenda, participants' meeting packet, and evaluation summary of meeting. Activities 4.2.1, 4.2.2, and 4.2.3 are updated as needed through Year 2.

OBJECTIVE 5.1: In Year 1, develop a plan to identify infants tested that passed hearing screening prior to discharge and later found to have a hearing loss at 3 or 4 years of age by matching Guam ChildLink data with GPSS Child Find data, GEIS data, or through the Guam EHD Parent-to-Parent Support Group. *Performance Measures:* Procedure Plan for Matching Data with Other Agencies and List of Children with Late Onset or Progressive Hearing Loss; "Analytical Plan for improving EHD Services Using Guam ChildLink" is developed in collaboration with relevant EHD agencies and the Guam EHD Advisory Committee. Activity 5.1.1 is ongoing through Year 2.

OBJECTIVE 5.2: Conduct an in-depth case analysis, quarterly, 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. *Performance Measures:* Case Study Report on all children born on Guam found to have late onset or progressive hearing loss. Activity 5.21 will be completed 2nd quarter Year 2.

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. Each year methods to improve the quality of Guam ChildLink's performance and usefulness will be reported in the Guam EHD annual report. *Performance Measures:* First working draft of Guam EHD Quality Assurance Plan; Complete draft of Guam EHD Quality Assurance Plan, feedback reports from reviewers; Final copy of the QA plan is on file and disseminated to listing of individuals/agencies developed in Activity 3.3.3. Activity 5.3.2. By the 3rd quarter of Year 2, the Project Director and Project Coordinator will have a complete draft of The Guam EHD Quality Assurance Plan ready for review. *Performance Measures and Timeline:* Complete draft of Guam EHD Quality Assurance Plan, feedback reports from



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reviewers, i.e. Guam EHDHI Advisory Committee, agencies, etc. Activity 5.3.3. By the 2nd quarter of Year 2 the Guam EHDHI Quality Assurance Plan will be completed and disseminated. *Performance Measures and Timeline:* Final copy of the QA plan is on file and disseminated to listing of individuals/agencies developed in Activity 3.3.3.

For next budget period, all activities will remain the same and there are no new activities at this time. Furthermore, there are no anticipated issues at this time that will hamper the success or completion of the project.