PROGRAM NARRATIVE

1. Summary of overall project accomplishments during the reporting period, including any barriers to progress encountered and strategies/steps taken to overcome them

The Hawai'i Baby Hearing Evaluation and Access to Resources and Services (Baby HEARS) Project aims to reduce the number of infants and families that are lost to follow-up/ documentation (LFU/D). Project accomplishments include:

- The Newborn Hearing Screening Program (NHSP) is participating in the National Initiative on Child Health Quality (NICHQ) Learning Collaborative B. Goals of the Hawai'i Team are to decrease loss to follow-up at second screen by 50% of babies who do not pass or miss the first screen; decrease loss to follow-up at diagnostic evaluation of babies who do not pass the second screen, excluding Neonatal Intensive Care Unit (NICU) babies; and decrease loss to follow-up at intervention by 30% of babies with confirmed hearing loss. The team is working on the following improvement activities:
  - Develop care plans (roadmaps) for children who do not pass the initial newborn hearing screen, which will be given to families before hospital discharge or at the outpatient stage, as well as at each subsequent stage in the evaluation and referral process.
  - Increase contact with the primary care physician (PCP) for children who do not pass the initial newborn hearing screen by sending a letter and a copy of the care plan.
  - Improve the hospital data input system to include multiple family contact information by providing training and support to hospital staff.
  - Create a script for hearing screeners giving screening results to families.
  - Increase parent-to-parent support to families with children with confirmed hearing loss.
  - Request audiologists to forward diagnostic reports to NHSP.
- NHSP protocol was updated to include calls to doctors for assistance when children are referred to NHSP for follow-up. If a family was lost to contact for rescreening or evaluation after the infant was discharged from the hospital, NHSP staff work with the medical home providers to follow-up with the family.
- A Baby HEARS Parent Coordinator has been hired to contact families and offer family support and consultation at the screening/rescreening stage, evaluation stage, after diagnosis of permanent hearing loss, and after early intervention enrollment. The Parent Coordinator facilitates monthly parent support group meetings, coordinates quarterly training opportunities for families, conducts family satisfaction surveys, collaborates with professionals, and offers training and perspective from a parent's point of view.
- NHSP collaborated with the Early Intervention Section (EIS) to add a field to the EIS database to indicate whether or not early intervention (EI) families have given their consent to share information with NHSP. Electronic matching of the EIS and HI*TRACK databases helps to identify children receiving EI services who have been LFU/D for newborn hearing screening or evaluation. It also helps to identify children who may have late-onset hearing loss. This allows NHSP to contact the EIS care coordinator who can follow-up with children who did not pass screening or complete the

diagnostic evaluation. EIS provides EI services as mandated by Part C of the Individuals with Disabilities Education Act (IDEA).

- The NHSP, working with the Children with Special Health Needs Branch (CSHNB) Research Statistician, continues to monitor the percentage of children meeting the 1-3-6 Early Hearing Detection and Intervention (EHDI) timelines or who are LFU/D at the screening, evaluation, or intervention stages. Data are used to document progress, for planning purposes, and for quality improvement. Data for 2005-2008 (table below) show fluctuating rates, with no clear trend toward improvement. Data show the need to continue efforts, including the Learning Collaborative quality improvement activities, to reduce the loss to follow-up. NHSP challenges include vacant positions in 2008, relatively new staff who need to both learn and improve the newborn screening/follow-up system, State's economic crisis with hiring restrictions and furloughs, lengthy procurement process for high-cost items, and insufficient staff time to carry out Learning Collaborative and other activities.

	2005	**2006**	**2007**	**2008**
Screening				
% screened by age 1 month	97.6%	98.3%	98.1%	97.3%
% LFU/D at screening stage	0.9%	0.9%	0.8%	1.1%
% births out-of-hospital (homebirths) LFU/D at screening stage	68.1%	60.7%	43.1%	72.7%
Evaluation				
% evaluated by age 3 months	48.9%	50.2%	39.1%	41.3%
% LFU/D at evaluation stage	42.7%	31.9%	44.8%	41.3%
Intervention				
% receiving early intervention by age 6 months	81.0%	72.6%	72.6%	59.0%
% LFU/D at intervention stage	1.6%	3.7%	3.2%	1.6%

Barriers to progress that the NHSP has encountered and strategies/steps taken to overcome them are listed below.

Challenge	**Approach to address challenge**
Vacant NHSP positions during 2008. NHSP staff is relatively new, employed since March 2008 and later.	• All staff has been quickly learning the newborn hearing screening and follow-up system, are working toward improvements where possible, and are building working relationships with hospital newborn hearing screening coordinators, audiologists, early intervention care coordinators, and others. • NHSP participation in the NICHQ Learning Collaborative B is supporting NHSP staff in learning a systematic approach to quality improvement that can be applied in various program areas.

	• The CSHNB Chief and EIS Supervisor work with the NHSP Coordinator to provide information, guidance, or assistance as needed.
State's economic crisis, with hiring restrictions, state funding restrictions, and furloughs. Furloughs are 2 days per month, from October 2009 to June 2011. The Office Assistant position, vacant since October 2008, will be filled in December 2009, but deployed to another part of EIS due to staff shortages due to Reduction-in-Force.	• NHSP staff is "doing their best" to manage within work constraints. Furloughs will require that staff prioritize their work using the EHDI 1-3-6 goals and reduction in LFU/D rates as a guide. • Activities that improve efficiency (e.g., upgrade to HI*TRACK 4, or decrease the number of children requiring follow-up by updating aging screening equipment or increasing access to screening in communities) may balance the decreased staff work time due to furloughs and due to staff shortage.
Timely purchasing of equipment due to a lengthy procurement process.	• NHSP staff started the procurement process (including procedures, forms, bids, quotations, etc.) upon notice that supplemental funding was awarded.
Different ways to establish community sites for hearing screening or expanding audiologist services for diagnostic evaluations on Neighbor Islands.	• NHSP will use the NICHQ Learning Collaborative model of improvement, which uses a Plan-Do-Study-Act (PDSA) cycle to test and implement changes. Where possible, activities will start on a small scale, be evaluated/tested, before expansion on a larger scale.
Lack of reporting by one hospital of screening results at an individual child record level to the DOH/NHSP.	• The administrative rules that include requiring birthing facilities to report newborn hearing screening results to the DOH have been reviewed by the Deputy Attorney General (AG) and have been revised per the AG comments. The new NHSP Coordinator has reviewed the draft rules and may revise the rules to improve follow-up procedures; this will entail additional reviews and approvals before the final step of public hearings and Governor's approval.
Need to increase midwife referral of out-of-hospital births for newborn hearing screening.	• NHSP works in collaboration with Newborn Metabolic Screening Program (NBMSP) to provide outreach to midwives on Oahu and the Neighbor Islands. However, the NBMSP Coordinator will retire in December 2009, and NHSP will need to take a more direct role in outreach to midwives.
Loss to follow-up due to changes in contact information. This is especially a concern on the Neighbor Islands where many families use the post office	• NHSP identifies child's medical home and ask medical providers to contact the family. The medical providers can inform the family about hearing screening and the importance of intervention if hearing loss is detected, and help to schedule follow-up. • NHSP continues collaboration with CSHNB Research

box as their mailing address. After the infant is discharged from the hospital, the family may be lost to contact if they do not respond to mail regarding rescreening or evaluation appointments.	Statistician, Office of Health Status Monitoring, NBMSP, and EIS to identify children who are LFU/D for hearing screening and evaluation. • One of the Learning Collaborative quality improvement activities is to educate PCP to access hearing screening results via other sources like the electronic medical record, discharge report, or hospital face sheet so conversation regarding baby's hearing follow-up can be initiated as early as the first well-check appointment.
Some infants with confirmed hearing loss do not receive EI services by six months due to repeated testing by audiologist before confirming hearing status.	• NHSP works closely with audiologist and the audiologist consultant to ensure timely evaluation and to refer children with risk factors to EI services after they fail the initial screen.

2. Progress on specific goals and objectives, including the specific strategies enumerated under the program purpose

Goal 1: To increase the percentage of children meeting early hearing detection and intervention (EHDI) 1-3-6 timelines.

Objective 1.1 By March 31, 2011, increase percentage of infants screened for hearing loss by age 1 month to 98%, percentage of infants with possible hearing loss who have audiologic evaluation by age 3 months to 70%, and percentage of infants with hearing loss who are enrolled in appropriate intervention services by age 6 months to 85%.

Activity 1.1.1 Expand state follow-up procedures to increase direct contact with primary care providers and Part C care coordinators to assist in meeting 1-3-6 EHDI timelines.

- The NHSP protocol was updated. When NHSP staff receives referrals from the hospital, they contact child's PCP to discuss referrals. When NHSP is unable to contact a family because of insufficient information, staff call the PCP's office and most of the time, staff are able to obtain the contact information and the second point of contact information.
- If NHSP initiates the referrals for evaluation to Kapiolani Medical Center for Women and Children (KMCWC), the audiologist sends copies of evaluation report to NHSP and PCP. When a child has confirmed hearing loss, NHSP will contact child's PCP to ensure that the doctor discusses diagnosis and follow-up needs with the parents. If EI services are needed, NHSP will follow-up with referral to Hawai'i Keiki Information Service System (H-KISS), the intake component of EIS.
- In July 2009, NHSP collaborated with H-KISS to streamline the referral process. When H-KISS received referral from NHSP, within 2 weeks H-KISS sent a letter to NHSP to inform the status of the referral (family referred to a care coordinator, family refused EI services, or H-KISS failed to contact the family). If H-KISS was not able to contact the family or the family refused EI services, the Parent Coordinator attempted to contact the family and provide support if needed. If family changed its mind, another referral to H-

KISS was initiated.

- In October 2009, EIS changed the H-KISS policy due to a federal Office of General Council (OGC) requirement. The response letter to NHSP will now only acknowledge receipt of the referral, except that when H-KISS fails to contact the family, it will be explained in the letter. NHSP needs to develop new strategies, such as contacting the family directly or getting information from the PCP, to confirm the enrollment of family in EI Services.

Activity 1.1.2 Educate program staff, screeners, audiologists, and primary care providers about the importance of meeting 1-3-6 timelines by providing training, technical assistance, and written materials.

- The Hawai'i Practitioner's Manual for Early Hearing Detection and Intervention is widely used by providers as a reference. NHSP continues to send copies to new PCPs or upon request by providers.
- The NHSP Coordinator, Baby HEARS Coordinator, and/or the American Academy of Pediatrics-Hawai'i Chapter (AAP-HI) EHDI Champion have scheduled visits to all birthing hospitals. The purpose of the visit is to review the 1-3-6 timeline, discuss issues and challenges, and provide technical support on screening and data input. NHSP staff explain the role of NHSP office and the important data required in HI*TRACK. In year 2, site visits were made to Queen's Medical Center, KMCWC, Wilcox Medical Center on Kauai, Hilo Medical Center, and Imua Program on Maui. Visits to other hospitals will be completed by December 2010.
- NHSP reprinted the "Universal Newborn Hearing Screening" brochure in English and 11 other languages. These brochures were distributed to the birthing hospitals. Each family was provided a copy of the brochure before or after the baby received screening.

Activity 1.1.3 Identify/provide necessary screening and diagnostic equipment, lending library materials, and loaner FM systems and hearing aids to support appropriate and timely EHDI services.

- NHSP, in collaboration with the Children with Special Health Needs Program (CSHNP), continues to loan hearing aids and FM Systems throughout the state to families via pediatric audiologists. All but one of the existing hearing aids and FM systems are broken, having missing pieces or are lost. We are in the process of purchasing ten new hearing aids to replace the old ones.
- NHSP purchased three loopback cables and two ear probe cables for the echo-screen machine. The loopback cables were sent to Hilo, Castle, and Kona Medical Centers. The ear probe cables were sent to Castle and Kona Medical Centers. All birthing hospitals that have the loaner echo-screen equipment from NHSP now have their own loopback cable to calibrate the screening equipment. Previously, the hospitals shared the cable and waited for it to be mailed by the previous user before they could calibrate their equipment.
- NHSP and the EHDI Advisory Committee recognized the importance of two-stage screening to minimize unnecessary referral for evaluation. NHSP staff started the

procurement process to purchase two hearing screening equipment which has the capacity to do the two-stage screening. This equipment is to replace the old ones at West Kauai and Molokai Medical Center. In Year 3, the one in North Hawaii will be replaced.

Objective 1.2 By March 31, 2011, implement monthly quality assurance activities to monitor timelines, identify service gaps, and evaluate progress.

Activity 1.2.1 Facilitate monthly data collection and analysis by state follow-up team and quarterly analysis by EHDI Advisory Committee, and recommend strategies to address concerns.

- Training was provided for the new Baby HEARS Project Coordinator on how to conduct monthly data collection/analysis and joint quality assurance with the NBMSP. Quarterly matching of NHSP and NBMSP with vital records provides data on children screened and not screened.
- Each hospital (except Kaiser which only provides an annual report with numbers) sends monthly birth census and screening results to NHSP by the 10th day of the following month. The Project Coordinator collects and merges all data, performs analysis, and sends data to the CSHNB statistician for data matching with NBMSP and quarterly matching with vital records.
- The Project Coordinator now reviews data monthly. If the Project Coordinator has questions about status of the screening result of an individual child, she contacts hospital staff to clarify or sends a referral to the Social Service Assistant to follow-up with the family or the PCP.
- NHSP Coordinator conducted the first quarterly report which includes data on number of children screened, number evaluated, number with confirmed hearing loss, number enrolled in EI services, and number lost to follow-up. Quarterly reports were sent to individual hospitals. Two hospitals responded and provided updated information due to discrepancy in HI*TRACK data between hospital and NHSP. NHSP will continue to prepare the quarterly report and share the information with the hospitals.
- The annual Hospital Newborn Hearing Screening (NHS) Coordinators meeting was held in April 2009, and the EHDI Advisory Committee meeting was held in July 2009. The annual newborn hearing screening data were shared at the meetings and suggestions for improvement in loss to follow-up were discussed.
- The annual Pediatric Audiology Committee meeting will be scheduled in January/February 2010. The purposes of the meeting are to discuss family-centered services, utilization of roadmaps, scheduling of evaluation appointments, and preparing the Authorization for Services (AFS) request.

Activity 1.2.2 Facilitate piloting/implementation of strategies to better meet 1-3-6 timelines, address service gaps, and evaluate progress (working with state follow-up team, EHDI Advisory Committee, and/or other committees).

- NHSP purchased 25 copies of the "Newborn Hearing Screening Training Curriculum, Competency-based Training for New Hearing Screeners" developed by the National Center for Hearing Assessment and Management (NCHAM) and distributed to all

birthing hospitals. The DVD can be used as a self-administered training tool for new screeners and refresher training for experienced screeners.

- Strategies to reduce LFU/D were discussed at the Hospital Newborn Hearing Screening Coordinators Committee and the EHDI Advisory Committee meetings. Some of the suggestions were piloted at selected sites using the Learning Collaborative B model of change: the Plan-Do-Study-Act (PDSA) cycle. An example of an activity to verify PCP information was to send a list of children without PCP names to the NBMSP and have the CSHNB statistician provide the PCP names from the merged data. NHSP staff then called the PCP office to confirm if the child is the patient.

Activity 1.2.3 Identify/provide computer equipment, software, and training to support timely EHDI quality assurance activities and statewide data collection/linkages.

- NHSP has arranged with NCHAM on the continued use of HI*TRACK 3.5 (HT3.5) software/database for all birthing hospitals and the state NHSP, including Help Desk support.
- NHSP has begun the procurement process to convert the HT3.5 database to HI*TRACK 4 (HT4). If approved, the initial conversion will be at the NHSP office. NHSP staff and CSHNB statistician will be trained to use HT4 to do data merge, follow-up tracking, and quality assurance. Staff will receive training from the Help Desk. HT4 enables easy tracking of children who need follow-up evaluation or EI services, and therefore will help to decrease the number of lost to follow-up.
- In Year 3, the HI*TRACK database system will be upgraded to HT4 at all birthing hospitals. Hospital staff will receive training to input and transfer screening data using HT4. After HT4 is installed at all facilities, NHSP will contract a NCHAM consultant to travel to Oahu and possibly Neighbor Islands to provide onsite training on use of the new version. It is expected that HT4 will be fully implemented at all sites by March 2011.
- Computer support to NHSP continues to be provided by the EIS Information Technology Specialist. Data support to NHSP is provided by the CSHNB Research Statistician.

The supplemental application objectives (renumbered to Objectives 2.3, 2.4, and 2.5 below) are included in Goal 2.

Goal 2: To decrease the percentage of children lost to follow-up/lost to documentation (LFU/D).

Objective 2.1 By March 31, 2011, decrease percentage of children born in locations other than birth hospitals who are LFU/D at the screening stage to 30.0% and maintain birth hospital percentages under 1.0%.

Activity 2.1.1 Expand state follow-up procedures to increase direct contact with primary care providers and collaboration with Part C Early Intervention to assist in reducing LFU/D at the screening stage.

- EIS policies include having written parent consent to share information with NHSP and for care coordinators to obtain hearing screening results for all enrolled children. NHSP

provides screening result from the HI*TRACK database system and informs the EI care coordinator if a child needs hearing follow-up

- Several NICHQ Learning Collaborative PDSA cycle activities focus on increase direct contact with PCP and increase physician education:
  - When a child has hearing loss and NHSP receives the evaluation report, the Social Service Assistant calls the PCP office to confirm diagnosis and discuss follow-up needs.
  - The hospital faxes a copy of the roadmap to the PCP within 48 hours. The roadmap is shared with the parents.
  - Some hospitals have an electronic medical record system and newborn hearing screening results are entered into the system. NHSP and the AAP-HI EHDI Champion are planning a campaign to encourage PCPs to access screening results from the electronic medical record, since information is available much sooner than the screening letter sent through mail from the hospitals.

Activity 2.1.2 Facilitate piloting/implementation of strategies to increase access to screening for children born in locations other than birth hospitals and for children residing in rural areas on Oahu and Neighbor Islands (working with state follow-up team, EHDI Advisory Committee, and/or other committees).

- When the NHSP Coordinator and the Baby HEARS Coordinator visit the birthing hospitals, issues about screening children born in other locations are discussed. Hospitals are encouraged to screen homebirth infants and NHSP assists in developing the protocols and the process of entering data in HI*TRACK.
- NHSP staff is exploring community facilities, such as community health centers, Public Health Nurses, and/or pediatrician offices who are interested in screening infants who are not born at a birthing hospital or who reside in rural areas and have difficulty returning to their birthing hospital for outpatient screening. NHSP may provide loaner screening equipment and training if such facility is identified.
- Two NHSP staff (Project Coordinator and Parent Coordinator) was trained by the audiology consultant to do hearing screening. They will pilot hearing screening at the family's home if the homebirth families are not able to travel to a screening site on Oahu.

Activity 2.1.3 Facilitate piloting/implementation of strategies to increase data linkages across Department of Health (DOH) programs to assist in locating children LFU/D at the screening stage.

- EIS is implementing a new database system and the consent field was added to indicate whether families have consented to share information with NHSP. EIS generated its first periodic report in October 2009 to NHSP of all children enrolled in EI services receiving hearing services whose parents had signed the consent form. NHSP staff and CSHNB Statistician match the EIS and HI*TRACK databases to confirm that children with hearing loss are receiving EI services and also to identify children with hearing loss who are not known to NHSP.
- NHSP is exploring with the CSHNB Statistician about NHSP obtaining PCP and

insurance information through matching of NHSP data with NBMSP data and vital records.

Objective 2.2 By March 31, 2011, decrease percentage of children LFU/D at the evaluation stage to 15.0% and percentage LFU/D at the intervention stage to 3.0%.

Activity 2.2.1 Expand state follow-up procedures to increase direct contact with primary care providers and collaboration with Part C Early Intervention to assist in reducing LFU/D at the evaluation and intervention stages.

- When a child has hearing loss and NHSP receives the evaluation report, the Social Service Assistant calls the PCP office to confirm diagnosis and to discuss follow up needs. (see activity 2.1.1)
- The Parent Coordinator was invited to support parents at an evaluation appointment at the KMCWC Audiology Clinic, in response to a need expressed by parents. The Parent Coordinator also accompanies EI care coordinators on home visits. The Parent Coordinator does not do case management.
- When a child is referred to H-KISS and the response letter indicates that the child is referred to an EI program, the Social Service Assistant contacts the EI program to confirm the EI Care Coordinator. If the information about EI enrollment is unavailable, the Social Service Assistant attempts to find out from the PCP and/or the parents. If the parents refuse EI services, a referral is made to the Parent Coordinator to follow up.

Activity 2.2.2 Facilitate piloting/implementation of strategies to increase access to evaluation for children residing in rural areas on Oahu and Neighbor Islands (working with state follow-up team, EHDI Advisory Committee, and/or other committees).

- NHSP Coordinator has scheduled an appointment with a pediatric audiologist who has diagnostic equipment on loan from NHSP. The meeting is to discuss the logistics for this audiologist to service the Neighbor Island children.
- NHSP will continue to explore with pediatric audiologists about their traveling to the Neighbor Islands to perform evaluations.

Activity 2.2.3 Facilitate piloting/implementation of strategies to increase data linkages across DOH programs to assist in locating children LFU/D at the evaluation and intervention stages.

- NHSP collaborated with Part C Early Intervention to facilitate electronic matching with the EI database, in order to identify children who were LFU/D at the evaluation stage. This will allow NHSP to follow-up with EI care coordinators regarding completion of the diagnostic audiological evaluation. See Activity 2.1.3.

Objective 2.3 By August 31, 2011, decrease by 20% the number/proportion of children who are LFU/D for screening.
(Baseline: In 2008, 1.3% (249/19,453) births were LFU/D for screening.)

Activity 2.3.1 By September 2009, NHSP staff will be responsible for follow-up, including interim care coordination as needed, for families of infants who fail newborn hearing

screening.

- The Social Service Assistant was assigned to be the interim care coordinator for families of infants who fail hearing screening and need evaluation or who have confirmed hearing loss and need intervention.
- The procedures for hospital screeners to refer infants who fail screening to NHSP are currently implemented inconsistently. NHSP has started and will continue to work with individual hospitals to revisit the procedures to ensure timely referral of infants who fail screening.
- The Baby HEARS Coordinator is responsible to compile monthly screening data. When the hospitals submit monthly data to NHSP, the Baby HEARS Coordinator merges all data, erases possible duplicated records, contacts the hospital staff if additional information is needed, and generates a list of infants who need evaluation or screening. The list is shared with the Social Service Assistant for follow-up.
- A tickler file of infants who need follow-up evaluation or intervention is periodically generated. The Social Service Assistant is responsible to coordinate with parents and PCP to ensure diagnostic appointments or EI referrals are made. The Social Service Assistant will also make a referral to the Parent Coordinator if parent support is needed.
- For quality assurance purposes, the NHSP coordinator generates quarterly reports on the number of infants born, screened, evaluated, and missed screening (lost to follow-up) based on HI*TRACK information. This report is sent to each individual hospital. The list of infants who missed screening may be verified with individual hospitals to determine whether there are discrepancies in HI*TRACK data or they are "true" loss. The Social Service Assistant will attempt to follow-up with the PCPs and/or the parents of infants who are confirmed to have missed screening.

Activity 2.3.2 By August 2010, utilize a roadmap to guide parents through the process of screening, evaluation, and intervention.

- A major activity of the NICHQ Learning Collaborative B-Hawai'i Team is to design and utilize a roadmap to guide parents through the screening, evaluation, and intervention process. In Year 2, two versions of roadmaps were adapted, modified, and field tested at the two pilot hospitals. The hospital screeners write the outpatient appointment date and share the roadmap with families prior to discharge. If the infant is referred for evaluation and intervention, the same roadmap is utilized with information added at each stage. Copies of the roadmaps are faxed to the PCP. Hearing screening information was provided on the back of the roadmap for parents' reference. A script about how to talk to the parents and frequently asked questions/answers information sheet was developed for screeners to use when they share the roadmap with the parents. Hospital screeners complete a feedback form on every roadmap they share and send the form to NHSP. NHSP staff modifies the roadmap and script based on the feedback received.
- By March 2010, the roadmap will be finalized and implemented statewide.

Activity 2.3.3 By December 2010, 80% of birthing hospital will implement two-stage screening (OAE and ABR).

- NHSP works with all birthing hospitals to ensure their screening equipment have both OAE and ABR screening capability. NHSP staff is now in the process of purchasing screening equipment for hospitals that need upgraded equipment.
- AAP-HI EHDI Champion and NHSP staff traveled to Hilo in October and to Maui in November 2009 to provide training to screeners on the two-stage screening. Visits to all birthing hospitals to provide refresher training on the two-stage screening will be scheduled and completed by December 2010.
- The contracted audiologist consultant is available if hospital screeners need further support to implement two-stage screening.

Activity 2.3.4 By December 2010, 5 sites in the rural areas of Oahu and Neighbor Islands will perform outpatient hearing screening and rescreening.

- A nurse at a pilot hospital (on the island of Kauai) of the NICHQ Learning Collaborative Project will try to provide outreach screening at the family's home if the family is not able to return to the birthing hospital for outpatient screening.
- Two NHSP staff was trained to do hearing screening by the audiologist consultant. They are available to do outpatient screening in the rural area on Oahu upon request.
- NHSP will continue to explore other sites in rural areas of Oahu or on Neighbor Islands that may be interested in providing outpatient screening. NHSP will develop agreements with these sites, provide loaner screening equipment and training to screeners, and develop procedures/protocols for referrals.

Activity 2.3.5 By September 2010, work with the midwife association to provide information about newborn hearing screening and where infants can get screening (hospital and community sites), and discuss how the process may be improved.

- NHSP will reach out to the midwife association and provide information on newborn hearing screening. A representative from the midwife association will be invited to be a member of the EHDI Advisory Committee.
- NHSP staff will compile a list of outpatient sites and birthing hospitals which agree to do hearing screening for homebirths. The list, together with a cover letter, will be sent to midwives statewide to inform them about the resources.

Activity 2.3.6 By August 2010 and ongoing, NHSP staff, contractors, and Hospital Newborn Hearing Screening Coordinators will have information related to cultural/linguistic competence, at least annually.

- NHSP staff and AAP-HI EHDI Champion are exploring speakers who may be available to present on cultural/linguistic competence at a hearing conference to be held in 2010. Target audiences of the conference are providers, parents, and hospital hearing screening staff. The training will include presentations on expectations and different language options from deaf parents or families of children with hearing loss.

Objective 2.4 By August 31, 2011, decrease by 25% the number/proportion of children who failed screening who were LFU/D for audiologic evaluation.

(Baseline: In 2008, 35.2% (83/236) of the referrals for audiologic diagnosis were LFU/D.)

Activity 2.4.1 By December 2010, upgrade HI*TRACK database system in all participating birthing hospitals to facilitate better data input and tracking.

- See Activity 1.2.3.

Activity 2.4.2 By March 2011, contract at least one pediatric audiologist to provide diagnostic evaluation on the Neighbor Islands.

- Currently, one pediatric audiologist has borrowed a diagnostic ABR equipment from NHSP with the commitment to do sedated ABR in Honolulu and diagnostic ABR on the Neighbor Islands. A meeting is scheduled with the audiologist in December 2009 to discuss the logistics of performing the ABR evaluation on the Neighbor Islands.
- NHSP will identify and contract another pediatric audiologist to travel to the Neighbor Islands to provide diagnostic evaluation. NHSP will provide loaner portable diagnostic ABR/OAE equipment to the contracted audiologist, assist in identifying a facility where the audiologist can perform hearing evaluation, and assist with scheduling the appointment with families. The pediatric audiologist will be required to provide a copy of the evaluation report to NHSP and will be responsible to follow-up if further testing is needed. A member of the Learning Collaborative team is willing to support and provide training to the contracted audiologist if needed.

Activity 2.4.3 By March 2011, sponsor at least two workshops and other training on newborn hearing screening to providers and other stakeholders.

- By March 2011, NHSP will sponsor at least one whole day or two half-day conferences and bring in national experts to provide education in hearing screening and related services. NHSP staff, audiologist consultant, and AAP-HI EHDI Champion have started planning for the conference. Several possible guest speakers have been contacted to explore the availability. The dates, location, theme, and target audience will be confirmed by March 2010.
- NHSP will sponsor community-based workshops related to reducing loss to follow-up for health care providers. The contracted audiologist consultant or AAP-HI EHDI Champion will provide training on Oahu and on the Neighbor Islands.

Activity 2.4.4 By September 2009, NHSP staff will be responsible for follow-up, including interim care coordination as needed, for families of infants who fail screening and need diagnostic audiologic evaluation.

- The Social Service Assistant serves as the interim care coordinator when an infant who fails hearing screening is referred to NHSP. The Social Service Assistant is responsible to follow-up with infants who miss or fail hearing screening identified from HI*TRACK database but are not referred to NHSP. He will contact the PCP and/or parents to confirm the needs for evaluation.
- The Social Service Assistant makes a referral to the Parent Coordinator if families refuse services or consistently miss appointments. Parent Coordinator will contact the parents and provide support if needed.

Activity 2.4.5 By August 2010, utilize a roadmap to guide parents through the process of evaluation and intervention.

- The same roadmap that was shared with families at screening will be used by audiologists to guide parents through the process of evaluation (see activity 2.3.2). If the infant has confirmed hearing loss, the same roadmap will be used to guide the parents through intervention. Utilization of the roadmap will be shared with pediatric audiologists via mail and at the annual providers meeting.

Objective 2.5 By August 31, 2011, decrease by 25% the number/proportion of children with permanent hearing loss who are LFU/D for early intervention (EI) services.
(Baseline: In 2008, 31.3% (20/64) of infants with permanent hearing loss were LFU/D for early intervention services.)

Activity 2.5.1 By December 2009, develop protocol and procedures for NHSP follow-up with EIS regarding the enrollment of infants with confirmed hearing loss into EI services.

- Protocols have been established for NHSP to refer infants with confirmed hearing loss to H-KISS, the EIS intake unit for EI services. When H-KISS informs NHSP that staff is unable to contact the family, the NHSP Parent Coordinator will contact the family to find out if further support is needed and encourage the family to proceed with the referral. Due to confidentiality issue, H-KISS can no longer inform NHSP if the family is referred to a care coordinator, and NHSP staff will follow-up with the PCP or the parents to confirm enrollment in EI. See Activity 1.1.1.
- NHSP staff will collaborate with CSHNB Genetics Program on establishing a protocol on referrals to the Hawai'i Community Genetics (HCG) clinic. An orientation training on HCG services is scheduled in November 2009 for NHSP staff and other interested providers.

Activity 2.5.2 By December 2009, develop protocol for NHSP to identify and follow-up for children in the matched EIS-HI*TRACK database who were LFU/D for audiologic evaluation, or had hearing loss and were not known to NHSP.

- See Activity 2.1.3.

Activity 2.5.3 By December 2009, provide parent support services for families of children undergoing audiologic evaluation, at the Audiology Department of the tertiary pediatric hospital in Honolulu.

- The KMCWC Audiology Department has requested the Parent Coordinator provide parent-to-parent support at audiological appointments for families of children with hearing loss. In September 2009, CSHNB/NHSP developed a Memorandum of Agreement with KMCWC (per KMCWC request) regarding its participation in the Learning Collaborative, which includes establishing protocols for the Parent Coordinator at audiological evaluation appointments with families.
- The Parent Coordinator will be available to accompany parents at evaluation appointments and provide counseling. The Parent Coordinator will also gather and provide resource materials for audiologists to share with parents.

Activity 2.5.4 By August 2011, establish administrative rules which require reporting of screening and diagnostic audiologic evaluations to the DOH.

- The administrative rules that include requiring birthing facilities to report newborn hearing screening results to the DOH have been reviewed by the Deputy Attorney General (AG) and have been revised per the AG comments. The new NHSP Coordinator has reviewed the draft rules and may revise the rules to improve follow-up procedures; this will entail additional reviews and approvals before the final step of public hearings.

Goal 3: To increase the percentage of families of children with possible or confirmed hearing loss who receive family-to-family support at the evaluation and intervention stages of the EHDI process.

Objective 3.1 By March 31, 2011, increase the percentage of families who receive family-to-family support at the evaluation and intervention stages of the EHDI process to 65.0%.

Activity 3.1.1 Contact families at the evaluation and intervention stages of the EHDI process to provide family support and consultation.

- Baby HEARS Parent Coordinator was filled as of 10/20/08. Letters were sent to Early Intervention providers and to parents of children with hearing loss to inform them about the availability of the Parent Coordinator. Contact information and referral forms were provided with the letter.
- NHSP developed the protocol that when a family refuses services for screening or evaluation, the Social Service Assistant refers the family to the Parent Coordinator, who will attempt to contact the family to provide support and to explain the importance of follow-up. If the family still refuses services, she will ask for permission to contact them later to check if the family's needs change.
- The Parent Coordinator with other NHSP staff coordinated three Ohana Time educational fairs for families this year. The themes for the Ohana Time were: Transition, Language Options, and Provider Resources. Guest speakers were invited to present on their area of expertise followed by potluck lunches, an opportunity for family to network and socialize with other families and providers. American Sign Language (ASL) interpreters were arranged upon request from families. Until the EIS Hearing Specialist position is filled, NHSP will continue to organize quarterly Ohana Time in Year 3. The Ohana Time may be rotated between Oahu and Neighbor Islands.
- In December 2009, the Parent Coordinator will coordinate with the Kapiolani Community College ASL training program to offer families of children with hearing loss the opportunity to visit a deaf Santa at a local shopping center on Oahu.

Activity 3.1.2 Educate program staff and health care providers about the importance of family-to-family support by providing training, technical assistance, and written materials.

- The "Sound Steps" resource guide for families of children with hearing loss was reprinted. When the Parent Coordinator visits and presents to providers, she shares the guide and explains how to use the guide with the parents. Extra copies of the Sound Step

are available for care coordinators upon request.

- The Parent Coordinator presented at early intervention programs and to Public Health Nurses on an orientation to NHSP and Parent Support services. She was invited to facilitate the parent support group meetings of the KMCWC rehabilitation services.
- The Parent Coordinator taught simple ASL to providers at the Hickam Air Force program and at the Hawaii Association for the Education of Young Children (HAEYC) Annual Early Childhood Conference.

Activity 3.1.3 Plan and coordinate periodic support meetings for families of children with hearing loss, and continue Deaf mentor pilot to provide American Sign Language (ASL) training and information about Deaf culture for families.

- Monthly Parent in Paradise parent support meetings are scheduled every second Sunday of the month.
- Contracted deaf mentors continued providing support to families of children with profound bilateral hearing loss.
- In the summer of 2009, an intern deaf student from Gallaudet University fulfilled her internship at EIS. She helped to research educational materials for parents, accompanied care coordinators on home visits, and presented and shared her experience growing up in a family with hearing parents and siblings. Her presentations were attended by families, EI staff, and EI contracted providers.

Objective 3.2 By March 31, 2011, implement survey process for obtaining information about family satisfaction, service gaps, and family support needs for review by the state follow-up team and EHDI Advisory Committee.

Activity 3.2.1 Draft family survey and survey protocol, review with state follow-up team and EHDI Advisory Committee to finalize, and implement.

- A parent survey was conducted as part of the prework of the NICHQ Learning Collaborative B. The survey indicated only two-third of the parents received information at the hospital about what to do when their babies fail screening and 44% had discussed the screening results with the PCP.
- Another NICHQ Learning Collaborative B prework activity was conducting a walkthrough at the Audiology clinic. At the walkthrough, staff observed hearing evaluations being performed and interviewed parents. Four interviews were completed. In general, parents felt the process of screening, referral, and evaluation was smooth and a "family centered approach" was used. However, they did not recall receiving hearing screening information or other resources before discharge from the birthing hospital.
- The Learning Collaborative team developed the aim statement of the project based in part on the information collected from this prework.

Activity 3.2.2 Collect quarterly data, facilitate analysis by state follow-up team and EHDI Advisory Committee, and recommend strategies to address concerns.

- At the Ohana Time, participants are asked to complete the evaluation/feedback form after

each session. Suggestions are incorporated in future planning. See Activity 3.1.1 for more information about Ohana Time.

Activity 3.2.3 Facilitate piloting/implementation of strategies to improve family satisfaction, address service gaps, and meet family support needs (working with state follow-up team and/or EHDI Advisory Committee & Subcommittees).

- A roadmap was drafted and piloted at selected hospitals to help parents navigate the process for screening, evaluation, and intervention. A script was drafted to assist hospital staff to explain the process of hearing screening and evaluation to the parents whose infants fail the initial inpatient screen. See Activity 2.3.2 for more information.

3. Current staffing, including the roles and responsibilities of each staff and a discussion of any difficulties in hiring or retaining staff

Position	General Responsibilities	Status
NHSP Coordinator (Children and Youth Program Specialist IV) – permanent state position	Oversees program activities throughout the state, supervises NHSP and Baby HEARS Follow-Up Project staff, drafts and implements program policies and procedures, conducts EHDI Advisory Committee and other committee meetings, gives EHDI presentations for hospitals and other providers, manages state hearing screening and tracking database, monitors data for completeness and accuracy including identification of missing data and duplicate record resolution, conducts record reviews and other quality assurance activities to identify and make recommendations regarding children needing follow-up, and drafts state/federal reports in coordination with Baby HEARS Project Coordinator, EIS Supervisor, CSHNB Statistician, and CSHNB Chief.	Po Kwan Wong (Children and Youth Program Specialist IV) was temporarily assigned to NHSP beginning 9/10/08, was the Acting NHSP Coordinator beginning 10/17/08, and has been the full-time permanent NHSP Coordinator position since 1/16/09.
NHSP Social Service Assistant V – permanent state position	Provides 1-3-6 timeline support, including working with hospitals on scheduling rescreens (if requested), contacting families, physicians, and audiologists to set appointments for evaluations, making referrals to EIS if permanent hearing loss is confirmed, drafting/printing form letters for families and physicians, etc. Also follows up with doctors by letter/phone on missed children identified through quality assurance and assists in database management and data analysis for state/federal reports.	Randy Lum has been in this position since 3/18/08.
Baby HEARS Project Coordinator –	Coordinates, facilitates, and monitors completion of Baby HEARS grant activities, including engaging hospitals and others in pilot activities,	Jasmine Jones has been in this position since 1/12/09.

Position	General Responsibilities	Status
exempt position	arranging and helping NHSP Coordinator conduct EHDI Advisory Committee and other committee meetings, drafting grant application narratives and progress reports, ordering materials authorized under the grant, tracking grant expenditures, helping Baby HEARS Parent Coordinator with family activities, presenting on EHDI topics at meetings, etc.	
Baby HEARS Parent Coordinator – exempt position	Coordinates, facilitates, and monitors completion of Baby HEARS family support activities with input from NHSP Coordinator, EIS Hearing Specialist, and Baby HEARS Project Coordinator. Facilitates family support meetings throughout the state, presents on family support and hearing loss at meetings, and calls families to offer family support during evaluation and intervention stages. Conducts family satisfaction surveys with input from Baby HEARS Project Coordinator and assists in writing grant progress reports.	Amanda Kaahanui has been in this position since 10/20/08.
Audiologist – contracted position	Gives input on NHSP policies and procedures, reviews incoming audiological evaluation reports, enters diagnoses in state database, makes recommendations to NHSP staff and care coordinators regarding follow-up, calls audiologists for clarification if needed, answers audiological questions by families, care coordinators, physicians, etc.	Amy Enright, contracted since 2006, provides 11 hours of audiological services per month.

The EIS Hearing Specialist became vacant on 10/20/08. This position had assisted in developing the resource guide for children with hearing loss and had coordinated the SKI-HI Deaf Mentor Pilot Program. All vacant positions are currently "frozen" with no hiring allowed because of the State's poor economic situation. It is unknown when hiring will again be allowed.

4. Technical assistance needs

Technical assistance needs include information, training, and support related to all aspects of EHDI implementation, including screening, diagnosis, and intervention. Technical assistance is currently received in several ways:

- The Newborn Hearing Screening Program (NHSP) is enrolled in the NICHQ Learning Collaborative B. The aim of the Learning Collaborative Hawai'i Team is to reduce lost to follow-up/documentation for screening, evaluation, and early intervention by improving communication with parents and medical home, strengthening screening data input, and increasing collaboration with other state and community programs.
- National Center for Hearing Assessment and Management (NCHAM) provides technical

support and consultation. NCHAM will provide the software and technical assistance to upgrade to the next version of the HI*TRACK database.

- Key individuals for this project attend the national Annual EHDI Conferences, which increases their knowledge and understanding of EHDI, and informs them of EHDI activities nationally and in other states.

5. Description of linkages that have been established with other programs

- **Title V/Children with Special Health Care Needs – Children with Special Health Needs Branch (CSHNB):** The CSHNB Chief provides general oversight for the NHSP, completes the NHSP/Baby HEARS Follow-Up Project grant applications and progress reports, and assists with NHSP data review/reports and planning. The CSHNB Research Statistician assists in analysis of NHSP data, links NHSP database with the NBMSP database and birth records, and provides data reports, including reports by the 1-3-6 timelines and LFU/D. The Title V Program currently has two performance measure related to newborn hearing screening and follow-up: National Performance Measure #12 – percentage of newborns who have been screened for hearing before hospital discharge, and State Performance Measure (SPM) #2 – percentage of infants with hearing loss who are receiving appropriate intervention services by age 6 months. NHSP reports on these measures for the annual Title V Maternal and Child Health Block Grant Application and Report. In addition, because SPM #2 is a Title V state priority, NHSP has provided various presentations and breakout groups on newborn screening follow-up.
- **Administrative Services Unit** provides fiscal support for the project including accounting, reports on grant fiscal status, oversight to ensure that appropriate fiscal procedures are followed, and provides information to NHSP on pertinent procurement procedures.
- **Newborn Metabolic Screening Program (NBMSP)** assures that all infants born in Hawai'i are satisfactorily screened for 32 disorders which may have serious consequences such as mental retardation or death if not identified and treated early. The program tracks and provides follow-up to ensure appropriate and timely screening, diagnosis, and treatment; sets standards/guidelines; and provides education to providers and general public. NBMSP has provided information regarding the NBMSP operation to NHSP. NBMSP and NHSP work together on education for midwives on the importance of newborn screening and providing informational materials for midwives to share with the mothers of homebirths.
- **Early Intervention Section (EIS)** is responsible for the statewide early intervention service system for children age 0-3 years who are developmentally delayed, biologically at risk, or environmentally at risk. Services are mandated by Part C of the Individuals with Disabilities Education Act (IDEA) and state law. EIS is responsible for the planning, development, and implementation of statewide early intervention services; assessment of needs and resources; and promoting public and private collaboration in the development of services. Services include assistive technology, audiology, family training, counseling, home visiting, health services, medical services (diagnostic/evaluation), nursing, occupational therapy, physical therapy, psychological, social work, special instruction, speech language pathology, transportation and vision services. NHSP has worked with EIS to ensure the timely referral of children with hearing loss to EI services, and on issues related to the sharing of

information regarding follow-up.

- **Children with Special Health Needs Program (CSHNP)** provides information and referral, outreach, care coordination, social work, and nutrition services for children with special health care needs age 0-21 years, including those with hearing loss. Financial assistance for medical specialty services (including ENT, audiological, and hearing aid services) is provided for eligible children who have no other resources. The CSHNP Audiologist works with NHSP related to CSHNB audiological services and payment rates, and has worked with the Department of Human Services/Med-QUEST Division regarding the Medicaid rates for audiological services including hearing aids. The audiologist also manages the hearing aid loaner program and is an active member of the NICHQ Learning Collaborative B team.
- **Genetics Program** plans, develops, and implements statewide genetics activities; assesses genetic needs in the community and develops policies and programs to meet the needs; develops activities to promote the prevention, detection, and treatment of genetic disorders; and provides genetics education for the professional and general community. The Genetics Program has been active in working with the NHSP related to genetic services for children with hearing loss.
- **Hospital Newborn Hearing Screening Programs:** The State NHSP has links with the Coordinators at all twelve birthing facilities, for information sharing, periodic meetings, discussion of needs, technical assistance, etc.
- **Deaf and Hard of Hearing Advisory Board:** Related to a proposed hearing and vision screening legislative bill, information about NHSP was provided at a legislative networking workshop for this Advisory Board 11/1/08.
- **EHDI Champion for the American Academy of Pediatrics-Hawai'i Chapter:** Dr. Lynn Iwamoto is the AAP-HI EHDI Champion. She and NHSP have worked together regarding presentations and continuing medical education sessions for pediatricians, family physicians, and other health care providers.
- **National Center for Hearing Assessment and Management (NCHAM):** NHSP Coordinator Po Kwan Wong met with Kim Aeill (NCHAM) on 12/3/08 and discussed availability of technical support and consultation provided by NCHAM. NCHAM provides the software and technical assistance for the HI*TRACK database, and will support NHSP in the upgrade to HT4. Louella Christensen, the former Hawai'i NHSP Coordinator, is now located in Illinois and is the NCHAM consultant. She is available to provide consultation and technical support to the Hawai'i NHSP and the database system.
- **Oral Cleft Clinic:** The KMCWC's Oral Cleft Clinic offers comprehensive medical care for children who have cleft lip and/or palate. NHSP staff collaborates with the CSHNP nurse at the clinic to ensure that children with hearing loss receive appropriate evaluation and follow-up care.