FY2013 Non-competing Continuation (NCC) Progress Report

Grant Number: **HRSA Grant H61MC00015**
Project Title: **Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening**
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PERFORMANCE NARRATIVE

Accomplishments and Barriers:

The ongoing focus of this grant is to reduce the number of children lost to follow-up and initiate earlier access to services by improving systems throughout the Early Hearing Detection and Intervention (EHDI) Program. During this reporting period, the Alaska EHDI Program continued to actively participate in the National Initiative for Children's Healthcare Quality (NICHQ) to strengthen collaboration with EHDI partners, as well as enhance parent support. Emphasis was placed on examining all components of the EHDI program and then, with input and involvement of families and community partners, employ quality improvement measures. Data analysis was ongoing throughout this process.

The Alaska EHDI Program assembled a core team to participate in the NICHQ. The team consisted of the EHDI Coordinator, a pediatric audiologist, an early interventionist and a parent navigator to attend the NICHQ trainings and participate in developing tests of change through Plan-Do-Study-Act (PDSA) cycles to implement quality improvement. Team members were consistent throughout the project, except for the change in parent navigators after Learning Session 2. In addition, extended partners from birthing hospitals, audiology practices, parents, early interventionists and representatives from the Governor's Council on Developmental Disabilities and Special Education remained engaged in the project and recommended strategies for implementation. Partners include representation from the private sector, native health system and military, as well as other state offices. The Alaska EHDI Advisory Committee continues to meet three times a year to review activities of the EHDI Program and recommend strategies to

reduce loss to follow-up and earlier access to services. Additional NICHQ extended partners have joined the Advisory Committee.

A significant accomplishment in the first grant year was improving the newborn hearing screening rate for out of hospital births in two communities, Fairbanks and Juneau. This was accomplished by placing hearing screening equipment at midwifery centers in those respective communities and providing training to the staff on the equipment and data entry. A Memorandum of Agreement (MOA) was signed specifying that the centers would report their entire census into the AKEHDI OZ database. Preliminary data from this second grant year indicates hearing screening rates for each of the two midwifery centers is at 90% - more than double the rate before the midwifery centers received the equipment.

The EHDI Program implemented a system utilizing newborn metabolic demographic data for earlier parent notification of screening requirements for out of hospital births. This process was written as a PDSA. Data indicates the following results for out of hospital births screened within 30 days: 2010 - 67%; 2011 - 73% screened and preliminary data for 2012 – 85% screened within 30 days. The EHDI brochure was modified specifically for this population.

A process was also established to provide midwives with a quarterly report on the number of infants in their practice that were screened. This process utilized the demographic data, and the primary care provider listed on the newborn metabolic screening (NBMS) card. This information was downloaded into the OZ database, an integrated database for NBHS and NBMS. In April 2012, the lab in Oregon, where NBMS is performed, began the transition to sending NBMS results using HL7 messages. At that time Oregon seized sending NBMS messages electronically, to the Alaska integrated database. This is a barrier to creating screening reports for the midwifery centers. The State of Alaska has pressed upon Oregon and Natus, contracted by the Oregon public health lab for the conversion, to solve this problem. This issue has significantly impacted the EHDI Program's follow-up with the out of hospital population and necessitated a work-around until the problem is fixed.

The EHDI Program continues to monitor facilities for their refer rate and loss to follow-up through a monthly fax-back system and quarterly practice profiles. The program identified that the two greatest areas of loss to follow-up were: 1) native health facilities discharging infants to rural remote regions of the state and 2) the largest military facility. The EHDI Program provided on-going technical support to these facilities. While these facilities did not engage in formal PDSA's, they participated in the NICHQ as extended partners and engaged in NICHQ activities. Both the military facility and Alaska Native Medical Center transitioned responsibility for newborn hearing screening to the newborn nursery, with referrals to their audiology departments. Responsibility for follow-up was delegated by each facility, resulting in a reduction in loss to follow-up/documentation for both facilities.

EHDI worked with the nurses in the newborn nursery of Alaska Native Medical Center (ANMC) on updating their EHDI protocol and data reporting requirements. This facility had a higher than expected refer rate, leading to more infants requiring follow-up. EHDI addressed this issue and worked with ANMC to develop strategies for reducing the number of false positives through staff training and designated staff administering screenings, timing of screenings and equipment checks. This facility reduced its overall refer rate from 7% in 2010, to 5% in 2011, to an acceptable rate of 3% in 2012. This resulted in 64% reduction in children needing follow-up between 2010 and 2012, representing 114 children in 2010 to 41 children in 2012.

Joint Base Elmendorf/Richardson (JBER) engaged in a year log process of reconciling data between the EHDI Program and JBER. This process involved all components of screening and follow-up at JBER: newborn nursery, pediatrics, audiology and a commander (with the rank of colonel), in a leadership role. Face-to-face meetings with key military personnel were held and a process for tracking screening and referrals to audiology was established. The facility is now uploading their demographic data electronically into OZ. This resulted in more accurate data. The number of children lost to documentation at that facility decreased from 66 in 2010 to 5 in 2011. Data for 2012 is not available at the time of this report; however raw data continues to show a decline from 2010.

The incentive program targeted for rural remote populations has encountered barriers related to "no shows", families relocating to different villages and weather (these villages are not on the road system); audiologist may be weathered out, as well as parents being "weathered in". Prior to the audiologist with the native health system traveling to these communities, the state was sending parents a letter and coupon for a gift card redeemable after keeping their appointment. In June of 2012, the incentive program was piloted in another rural remote region. This region is sending out the letters and coupons to parents from the native health corporation audiologist. Data from this trial will be analyzed after a full year of implementation.

The EHDI Program continues to collaborate with the Early Intervention/Infant Learning Program (EI/ILP) to improve the partnership between the programs with the goal of earlier referrals to early intervention. Participation of an early interventionist on the NICHQ Core Team increased the involvement and ownership of EI/ILP in this process. The early interventionist reviewed the one page EHDI Fact Sheet for Early Intervention with EI/ILP providers and it was favorably received. A process of sharing retrospective data between the two programs was developed and the programs are continuing to work on a process for sharing data in "real time".

NICHQ Extended Partner Meetings provided a forum for bringing together stakeholders around specific EHDI system "drivers". Several of these partners have joined the EHDI Advisory Meeting. The audiology packet developed during the NICHQ was successfully shared with other audiology practices. EHDI will continue to involve partners in the change process. There is an

improvement in early referrals to the EHDI parent navigator by audiology and access to parent support will remain a focus. The EHDI Program revised and redesigned a previously printed perpetual calendar which is distributed to new parents through the newborn nursery and midwifery centers statewide. The calendar contains developmental milestones and medical home information; the calendar is enthusiastically received (Attachment 3).

Goals and Objectives: The following is an update on strategies to meet specific goals and objectives.

Goal One: Ensure infants discharged from the hospital with a refer result or missed screen receive follow-up screening and/or early access to diagnostic information.

1.1 The EHDI Program will continue to monitor facilities with a high refer rates on a quarterly basis and target them for education.

The program continues to send practice profiles on a quarterly basis and review refer rates for each facility. Facilities with a high refer rate are contacted and remedies discussed. Alaska Native Medical Center (see above discussion) reduced its refer rate to within normal limits by revising their protocol and implementing stringent screening practices. Parameters were established on when infants are screened. The "Do and Don't" Communication card for screeners was laminated and placed by all screening equipment.

1.2 The EHDI Program will continue to monitor facilities with a high rate of missed screens and/or loss to follow-up on a monthly basis and target them for education.

The EHDI Health Program Associate has a system for monitoring facilities on a monthly basis to check for missing data. EHDI data is matched against newborn metabolic screening (NBMS) to determine if there is missing data. Facilities with incomplete data are contacted and remedies are discussed. The EHDI Program continues to send monthly faxes to facilities with incomplete data.

The EHDI Program was involved in a year-long communication with the largest military facility to improve data entry, tracking and follow-up. The head of pediatrics at this facility is a point person to follow-up on children with a missed or a refer on screening.

A one page fax back system for notifying primary care providers of children need follow-up was adapted from the NICHQ. This system is effective in getting a response from physicians. The EHDI Program is in the process of fully implementing the new "hearing reminders" enhancement to the database; this will support earlier notification to parents and providers of the need for follow-up.

The EHDI Program manager is working with the AAP Chapter Champion to implement a system for distributing *Just in Time* materials to providers when young children in their practice are newly diagnosed.

The EHDI Program Manager conducted site visits to two rural remote sub-regions, and to Fairbanks, the state's second largest population center, to discuss mechanisms for improving loss to follow-up. The discharge planner from ANMC was involved in these discussions to ensure a smooth transition from the hub hospital to rural locations. Site visits were conducted alongside ANMC audiology clinics. Quality improvement measures such as using a scripted message, making appointments before infants leave the hospital were discussed. Communities that have audiologists were involved in the meetings. Topical data calls were suspended as those facilities most likely to need intervention were least likely to call in. The above systems were implemented instead, focusing on communities requiring technical assistance.

1.3 By the end of 2011, the EHDI Program will analyze and measure the success of the incentive program for families in rural Alaska to return for a screen.

The incentive Program was modified to measure "small steps of change" and a PDSA was developed. It was trialed in remote communities based on the audiologists travel schedule. The program was hampered by weather and "no shows" so there is not sufficient data for analysis. The plan will be modified as appropriate. There are only two audiologists to cover a vast remote region. One of the two audiologists moved and now commutes from outside of Alaska. They are working on a plan to prioritize infants as their wait list is extremely long.

An additional incentive program was initiated in June 2012 at one of the remote regional hospitals with three audiologists on staff. Follow-up appointments will be linked to well baby appointments at the hospital clinic. Data will be analyzed after a year of data is gathered.

Goal Two: Ensure out of hospital births receive newborn hearing screening and appropriate follow-up in accordance with National EHDI 1-3-6 Goals.

2.1 By the middle of 2011, place screening equipment in two midwifery centers that have a high number of births and are in communities previously identified as having barriers to screening.

Screening equipment was placed at midwifery centers in Fairbanks and Juneau, two communities with a high number of out of hospital births, low screening rates and limited access to NBHS for infants born out of the hospital. Staffs at both midwifery centers were trained on the equipment and also on data entry. Both centers agreed to screen infants born at home or at another midwifery center. An MOA was signed with each center specifying duties and responsibilities. The screening rates at these facilities are currently at 90%. Two other midwifery centers requested screening equipment and the State is working with these centers on an MOA.

2.2 By the end of 2011, establish a process for quarterly communication with named and aggregate data for midwives on their screening rates.

A report was developed and was sent to all midwifery practices on a quarterly basis with a named list of infants associated with their practice and their screening results. Data from these reports will be analyzed by practice to determine if screening rates have improved and which practices may need more education. Reports to some of the midwifery centers were temporarily suspended as July 2012 secondary to the issues with the Oregon health lab described in the first section. EHDI is working on a system to run these reports while a remedy to the problem is sought.

2.3 By the middle of 2012, analyze data regarding the rate of change for numbers of newborns born out of hospital and screened as compared to baseline previously established.

A baseline for each midwifery center was established. The EHDI Program also implemented a system for contacting parents of out of hospital births by obtaining demographic data from the blood spot cards, rather than waiting for the monthly list from the Bureau of Vital Statistics (BVS), which was not always current. Earlier notification appeared to lead to earlier hearing screening for out of hospital births. In June 2012 the EHDI Program began sending letters to parents born out of the hospital by regular mail instead of certified. Data for 2012 will be analyzed to determine if there is a change in screening rates for this population. There has also been a lag in sending letters to parents as the State of Alaska Bureau of Vital Statistics (BVS) is in the process of converting to an electronic health record.

Goal Three: Establish a system of care connecting the EHDI Program with community partners and work with families of young children to ensure children are not lost to follow-up.

3.1 By the end of 2011, the EHDI Program will identify community partners with home visitation grants to offer technical assistance and education on the National EHDI 1-3-6 goals.

The State of Alaska (SOA) hired a program manager to oversee the contract for a home visiting site to implement in the Nurse Family Partnership in Anchorage. The contract for the Anchorage program was delayed until August 2012 and a supervisor was hired in November 2012. At this time they are working on program structure. The SOA program manager will serve as a liaison when staff is hired; EHDI can provide an in-service and technical assistance as needed. The EHDI Program manager will participate in the Advisory Committee. EHDI has identified the tribal home visiting programs, many of them newly staffed, and will be contacting them by the end of March 2013 to discuss newborn hearing screening and equipment needs and discuss opportunities for technical support around hearing screening for young children.

3.2 By the beginning of 2012, the EHDI Program will work with early childhood programs such as Early Head Start and Parents as Teachers to support screening activities and educational needs.

The EHDI Program developed a MOA and loaned screening equipment to the RurAL CAP Parents as Teachers Program (PAT). RurAL CAP serves low-income rural communities throughout the state. The MOA promotes the use of ECHO Project materials and the EHDI Health Program Associate initiated quarterly contact with this program and other Early Head Start and PAT Programs for offering support and equipment to support screening for young children. In addition to RurAL CAP, EHDI has screening equipment at the Early Head Start Program in Fairbanks and Southcentral Foundation in Anchorage. These programs all serve native populations. The EHDI Program contacted the SOA Early Childhood Specialist to explore options training and placing screening equipment at additional Early Head Start sites in the state. This objective will be continued into year three of this grant.

3.3 By the beginning of 2013, the EHDI Program will analyze data on the number of rescreens who would have been lost to follow-up and were screened at designated Federally Qualified Health Centers (FQHC) which are in rural subregional centers.

The EHDI Health Program Associate will contact the Sub-regional health centers to determine the status of hearing screening in those health centers and look at opportunities for linking this information back to the OZ database to reduce loss to follow-up. The DVD "Sounds of Silence" will be redistributed to community health centers.

Goal Four: Ensure infants/children diagnosed with a hearing loss receive seamless services from diagnosis through intervention in accordance with National 1-3-6 Goals.

4.1 By the end of 2011, the EHDI Program will analyze data entered into the EI/ILP module of the EHDI database for completeness and accuracy.

The EHDI Program Manager meets regularly with the State EI/ILP Health Program Manager. At this time EI/ILP is not entering data into the EHDI database. However, EI/ILP is working with EHDI to follow-up on children with hearing loss referred to EI/ILP by audiology and provides information back on their referral status. Audiologists were given a webinar on the EI/ILP module and documentation of referrals to EI/ILP by audiology has improved. The EHDI Program developed a one-page hand-out for EI/ILP providers on the importance of a release to EHDI. The new enhancements to the EHDI database will have a provision for notifying EI providers of a referral to EI/ILP for an infant with hearing loss.

4.2 By the end of 2012, the EHDI Program will analyze data on the time it takes for families to get enrolled in Early Intervention services.

The EHDI Program analyzed data received for infants born in 2010 for the CDC survey to determine the length of time from referral to enrollment. Of the children enrolled, 75% were enrolled before 6 months of age. Data for children born in 2011 will be analyzed by the end of March 2013.

4.3 By the beginning of 2013, the EHDI Program will analyze data on factors influencing the amount of time to receive Early Intervention service.

Options for an online survey will be explored. A telephone survey was conducted in July of 2010 with the assistance of a summer graduate intern from the Maternal Child Health (MCH) Bureau. Thirty-four parents were contacted and twenty-one responded to the survey. Parents interviewed reported it would be helpful to be immediately connected with a parent navigator at the time of diagnosis. Options for early contact are continuing to be explored in the next grant year. NICHQ activities appear to have resulted in an increase in referrals to the parent navigator.

Goal Five: Enhance family support to families of children requiring diagnosis and intervention services so that families partner in decision making and are satisfied with the services they receive.

5.1-5.3 These objectives address parent satisfaction, parent support, and early access to parent navigation will be addressed at the end of year 2 and continue into year 3 of this grant cycle.

Input from the parent navigator and parents on the EHDI Advisory Committee will be elicited to strengthen opportunities for parent support and receive feedback from parents on what manner of support would be meaningful. The parent navigator is entering data in the OZ database.

Significant Changes:

The EHDI Program consists of the EHDI Program Manager, who is responsible for the overall management of Alaska's Program and assessing success in meeting the National EHDI 1-3-6 Goals, as well as developing and promoting essential partnerships and leading the NICHQ core team. The Health Program Associate provides technical assistance to database users, assists with data entry, running reports, implements quality assurance procedures and enters data into the NICHQ Improvement Lab (Ilab). The EHDI staff is supervised by the Children's Health Unit Manager, who is in-kind on this grant. In September 2012, Thalia Wood left the position of Children's Health Unit Manager and the new manager is Rebekah (Becky) Morisse. Becky is also Co-Manager of the Newborn Metabolic Screening Program (biographical sketch attached). This position collaborates with EHDI on identifying trends and quality improvement measures.

There were no other changes to the project goals, objectives and timeframes and no new state staff is funded on this project.

Plans for Upcoming Budget Year:

The EHDI Program will be meeting with contacts from the community home visitation grants, including the PAT Program, Early Head Start and the Nurse Family Partnership Programs, to provide education and technical assistance on newborn hearing screening and follow-up. The EHDI Program purchased additional Otoacoustic Emission Screeners (OAEs) for distribution to programs. Training is proposed for this upcoming budget year. The Health Program Associate is setting up quarterly contacts with these programs to assure linkage to the ECHO Project resources, data collection and problem solve technical support issues.

The program will continue to collect data on out of hospital births and evaluate the efforts to improve hearing screening and follow-up for this population. A brochure on newborn hearing screening targeted for this population was revised and distributed. Quarterly reports will be reinstated when the HL7 issue is resolved with the Oregon lab. Plans to provide automated auditory brainstem response (AABR's) equipment to two additional midwifery centers are in process. These centers will also report their census into the OZ database.

The EHDI program is revising its letter and faxes with the goal of reducing loss to follow by earlier notification to parents, birth screeners, primary care providers, audiologists and early interventionists when an infant does not pass their newborn hearing screening. This revision is to complement the most recent enhancement to the OZ database called "hearing reminders". The hearing reminders will appear at intervals, determined by the state program, to provide timely notification. The reminders are system specific, customized to where infants receive their medical care: private, military or native health system. The Health Program Associate will have an essential role in configuring the reminders and implementing this new process. Changes in the loss to follow-up rate will be tracked.

The EHDI Program will continue to look at options for reducing loss to follow-up in rural remote regions of the state. Analysis of the incentive program will continue and modifications made to improve effectiveness.

The EHDI Program will continue to communicate and provide assistance to military facilities and provide reports and other forms of technical assistance to key military personnel. The program will look at opportunities to sustain the effectiveness of the program through staff rotations.

The EHDI Program Manager will continue to work with the AAP Chapter Champion and audiology to develop a packet of Just in Time materials that can be sent to the medical home at

the time children are diagnosed deaf/hard of hearing. Distribution of the audiology packet developed through NICHQ, along with revised Audiology guidelines will be explored.

Opportunities for utilizing parent navigation resources and enhancing parent support will continue to be explored. The parent navigator will continue to look into opportunities for establishing a Hands and Voices chapter in Alaska. She remains an active member of the EHDI Advisory Committee and will continue to work with another parent on the advisory committee to look at options for families who do not have insurance for audiology services. Soliciting parent input from an online or telephone survey is planned for year 3.

Methods for overcoming HIPAA/FERPA barriers will continue to be trialed with early intervention input. Opportunities for matching data with EI/ILP will remain a focus.

At this time, no carry forward funds are projected, unless there are expenditures associated with the EHDI Conference that are not captured in Budget Year 2. However, this will not be determined until the FFR is processed by the state fiscal office.