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PROGRAM NARRATIVE

INTRODUCTION:

The State of Alaska seeks support for the purpose of ensuring that infants born in Alaska are not lost to follow-up following a failed or missed hearing screening. Voluntary newborn hearing screening has been in place in all Alaskan birthing hospitals since December 2003. Legislation mandating newborn hearing screening was passed in May 2006 and regulations outlining the statute are effective January 2008. In accordance with the National Early Hearing Detection and Intervention (EHDI) 1-3-6 Goals, the mandate will require all birthing hospitals, audiologists, and early intervention programs to report screening and assessment results to the State's EHDI database. Continuation of federal funding in support of Universal Newborn Hearing Screening and Intervention (UNHSI) in Alaska will ensure that early identification, connection with diagnostic and treatment services, and early intervention are a well functioning system of care for all Alaskan children with hearing loss. (Note: UNSHI is hereafter referred to as the State EHDI Program, as this is the current vernacular for the Alaska State Program.)

Permanent hearing loss is among the most prevalent of congenital disorders, occurring in one to three per 1,000 live births (American Academy of Pediatrics Taskforce on Newborn and Infant Hearing. 1999; U.S. Public Law, 1998). By this estimate, approximately 10-30 newborns will be identified with hearing loss each year in Alaska. If left undetected, newborn hearing loss will impair speech, language, cognitive, and social/emotional development (American Academy of Pediatrics Taskforce on Newborn and Infant Hearing, 1999; U.S. Public Law, 1998). In the United States, hearing loss is more prevalent than any of the more than 30 metabolic disorders for which Alaska screens overall, approximately 1:10,000 (Oregon Public Health Lab Data; 2007). Nationally, over 50 percent of newborns with hearing impairments remain undetected until between the ages of two and three (Yoshinaga-Itano, C., Sedey, A., Coulter,D., and Mehl,A., 1998). Infants/children identified with hearing loss by six months of age demonstrate significantly better language scores than those identified after six months of age. For infants/children with normal cognitive abilities, a language advantage was evident for all ages tested, methods of communication, severity of hearing loss, and socio-economic status. The language advantage was also independent of gender, minority status, and the presence/absence of additional disabilities (National Center for Hearing Assessment and Management, 2000).

Universal Newborn Hearing Screening (UNHS) Programs that screen all infants will reduce the age at which infants/children with hearing loss are identified, improve school performance, reduce educational costs, and increase the likelihood that children who experience congenital hearing loss will be productive members of their communities (U.S. Public Law, 1998). UNHS is endorsed by the National Institutes for Health (NIH), Consensus Development Panel, the Joint Committee in Infant Hearing (JCIH), the American Academy of Pediatrics (AAP), the American Academy of Audiology (AAA), the Commission on Education of the Deaf, and *Healthy People 2010*.

Alaska is the largest of the 50 states and contains approximately 16 percent of the country's landmass or 586,412 square miles of land. The vast wilderness of Alaska is dotted with isolated villages, some with fewer than a dozen people. Many villages lack basic conveniences like running water and remain accessible only by small plane or boat. Intrastate air travel in Alaska often involves greater distances than interstate travel in the continental United States. Fares for air travel are expensive. Throughout rural Alaska, also called the Bush, very few local economies exist. Many residents live off the land and its wildlife, and survival depends on hunting, fishing, trapping, and gathering wild berries. Because of its size, Alaska has widely diverse geographic, climatic, and demographic characteristics, all of which affect public health. With diverse cultures, sparse populations, severe temperatures, vast coastline, and outdoor lifestyles, Alaska experiences many unique health care challenges. One such challenge is providing adequate and timely medical care and health care assistance to residents who live in remote areas of the state.

Alaska does not have a county structure and, while some boroughs have been formed, most have elected to not assume health powers. Much of the state remains "unorganized" with the state government fulfilling responsibilities otherwise normally handled by local county and municipal governments. Primarily, governmental health and social service functions have been, and continue to be, the responsibility of the state and federal governments - both of which increasingly carry out the services through various granting and contracting mechanisms. The Native health corporations, formed through a compact between the Indian Health Service, the

individual Alaskan tribes, and the State of Alaska, provide health care in these rural and bush communities.

Alaska's EHDI Program is located in the Children's Health Unit within the Section of Women's Children's and Family Health (WCFH). This section is one of nine sections in the Division of Public Health (DPH) which resides in the Department of Health and Social Services (DHSS). The section has taken a leadership role in promoting newborn hearing screening throughout the State of Alaska since 2001, having designated a staff position to oversee the goal of universal newborn hearing screening, detection and intervention. Currently, the State EHDI Program staff consists of a Program Manager and support from an Administrative Clerk. This year a Health Program Associate will be added to provide more advanced support and to aid in analysis of data from the EHDI database.

By 2003, all 21 birthing hospitals in Alaska were on board with newborn hearing screening. State facilitation assisted two communities – Barrow, in the extreme Northern Region of the State, and Juneau, in the Southeast region of the State – in obtaining hearing screening equipment with sponsorship from their local Lions Club. Through a partnership with Public Health Nursing, the section purchased and equipped eight Public Health Centers with ALGO-Automated Brainstem Response (AABR) screeners in regions of the State identified as either not having a birthing hospital or having a high rate of out of hospital births.

To track Alaskan infants across vast regions of the State and reduce loss to follow-up after newborn screening, the State of Alaska contracted with OZ Data Systems to implement a web-based data system. The database went "live" in June of 2005. It is managed by the Children's Health Unit in the Section of Women's, Children's, and Family Health. In 2005, staff from all twenty-one birthing hospitals and eight public health centers were trained on the database and these facilities are currently entering demographics and birth screening results into the database. The State EHDI Program facilitates ongoing database trainings to address the consequences of staff turnover and ensure consistency in data entry; three database trainings for newborn hearing screeners residing throughout Alaska were held in Anchorage in 2007.

Quarterly reports generated from the database and practice profile letters are sent to all birthing hospitals and public health centers on an ongoing basis. The reports detail how many infants were screened, how many passed their screening, how many had a refer and how many were missed. Refer is the common clinical term to indicate failure to pass a newborn hearing screening and this terminology is used by the State EHDI Program. The reports also indicate the refer rate for each hospital and the EHDI Program manager contacts hospitals with a high refer rate. These reports will also be utilized as a springboard to develop quality improvement models as proposed in this grant. In the past six months, the State's audiologists were trained on the database and are beginning to enter data. This is essential for tracking the timeliness of diagnostic follow-up for infants who did not pass their newborn screen. In the next phase, a process will be established for entry of data by the State Early Intervention/Infant Learning Program. Data integrity requires ongoing attention and will be addressed through advanced training of birth screeners and audiologists. In addition to practice profile letters and data teleconferences, the model for improvement involving small tests of change, developed by the National Initiative for Children's Healthcare Quality (NICHQ), will be implemented to test data integrity and reduce loss to follow-up.

The State EHDI Program promotes early hearing screening, detection and intervention through ongoing public awareness including brochures, manuals, an educational video, and television and radio public service announcements. The video, "*Sounds & Silence"*, was produced and distributed to rural health care providers in remote communities to increase their knowledge of early hearing detection and intervention for infants/children with hearing loss and monitoring infants/children with high risk factors for progressive hearing loss. The State continues to receive requests for the video from other states and countries facing similar rural health care challenges, such as Canada.

To outreach other ethnically diverse populations in Alaska and ensure their inclusion in the EHDI Program, the State EHDI brochure on newborn hearing screening and a follow-up brochure on "next step" for infants who failed their initial screening, were printed in five languages in addition to English. These brochures are available in Spanish, Hmong, Tagalog,

Russian, and Korean. The brochures are widely distributed throughout the state at birthing hospitals, primary care centers and public health centers.

The EHDI Advisory Committee, a group of diverse community stakeholders, was established in 2002 and continues to meet a minimum of three times per year to proactively promote the EHDI 1-3-6 National Goals in Alaska. Case reviews of children identified with hearing loss are presented at the Advisory Committee meetings. These case reviews provide continued quality assurance to the State EHDI Program and offers committee members the opportunity to network and to share ideas on how to improve services to families. In this forum, challenges and barriers to services are identified as well as areas in which technical assistance by the EHDI Program would be helpful to improve service delivery and assist in providing diagnosis and enrollment into early intervention services in a timely manner. Issues identified in this forum will generate models for quality improvement.

The Intervention Taskforce, a sub-committee of the EHDI Advisory Committee, met in March 2007 and broke into three smaller groups to address the following issues: 1) access to early intervention services, 2) identification and treatment for children with late onset and progressive hearing loss, and 3) follow-up for children with high risk factors in accordance with the recent 2007 Joint Commission on Infant Hearing (JCIH) guidelines. A fourth group is proposed to update the Alaska EHDI handbook, *Guidelines for Pediatric Audiological Assessment & Intervention,* to coincide with JCIH guidelines. The outcomes of these subcommittees will be a revised EHDI communication protocol to improve the system of referral and promote timely follow-up for infants/children from screening through intervention services. This protocol will be widely distributed throughout the State to birthing hospitals, birthing centers, public health centers, early intervention programs and primary care providers. The EHDI Program Manager and AAP Chapter Champion will continue to present in communities throughout the State, including Pediatric Grand Rounds presentations by the AAP Chapter Champion.

NEEDS ASSESSMENT:

There were 10,865 live births in 2006 with 305 births listed as birthing center births and 194 listed as home births for a total of 499 out of hospital births, representing 4.6% of all births in

Alaska (State of Alaska Bureau of Vital Statistics, 2006). Racial breakdown for children born in Alaska in 2006 is 7.5% Asian, 3.7% Black, 0.4% Native Hawaiian/Pacific Islander, 24% Native Alaskan, 62% White, and 2% is unknown. Despite the State's low population density, 65.6 % of the population was considered urban in 2000 (urban is defined by the 2000 Census). The remainder of the population live in rural and remote communities, most of which are not on the road system.

Recent data indicates the percentage of infants receiving hearing screens before hospital discharge increased from 81.1% in 2003 to 91.8% in 2006. As of 2005, this information is calculated from data in the database and prior to that time, from paper reporting. When factoring only infants born in hospitals, the percentage of newborn hearing screening is approximately 97% as calculated from State of Alaska Bureau of Vital Statistics information compared with the database entries.

Of the 10,220 infants entered into the State EHDI database for infants born in 2006, 9,648 infants are documented as having a newborn hearing screening. The refer rate for all hospitals was 4%. Practice profile reports are sent to all hospitals quarterly; these reports include documentation of the hospital's refer rate. The reports are reviewed by the EHDI Program Manager and outlier hospitals with high refer rates are contacted by the Program Manager. Of note, eight of the 21 birthing hospitals have less than 100 births per year; these hospitals may appear to have a higher refer rate in a particular quarter based on the small number of infant births. If an outlier has a consistently high refer rate, the hospital is encouraged to check their equipment and consult with the hearing screening vendor if the high rate persists. Having consistent staff conduct newborn hearing screenings also contributes to refer rates in the expected range. Birth screeners have also utilized the quarterly data teleconferences to problem solve screening/equipment issues.

Data from the State EHDI database indicate for infants born in 2006 that were entered into the database, 9% or 876 infants were in need of follow-up. Of those infants, 4% or 403 had a refer, and 5%, or 473 missed or had an undocumented screening. Of those 876 children, 19% are documented as receiving follow-up and 81% are recorded as "in process". The focus of this next

grant cycle will be to use models of improvement to follow-up on infants listed as "in process" to determine if they are lost to follow-up versus "lost to documentation". Emphasis will be placed on accurate data entry and improved tracking of children.

In the past six months, the state audiologists were trained on entering diagnostic information in the database. Additionally, an audiology user group, facilitated by OZ Data Systems has been established to facilitate easier data entry. These measures, along with the activities outlined in this grant will lead to improved reporting of the number of infants lost to follow-up between outpatient screening and audiological assessment. This information will also be required by the State's EHDI mandate which goes into effect in January 2008.

Tracking of infants from the time of diagnosis to entry into early intervention services will be emphasized in the next grant cycle. The Early Intervention/Infant Learning Program (EI/ILP) is in another division of the Department of Health and Social Services. At this time, the EI/ILP is not reporting name data to the EHDI Program for matching purposes. The EHDI Program has drafted a Memorandum of Agreement (MOA) with EI/ILP to receive data on children with hearing loss who are receiving EI services. This process has been affected by the Family Educational Rights and Privacy ACT (FERPA) and a plan for obtaining releases of information to collect this data will be addressed in the MOA. According to the State EI/ILP for children born in 2006, twelve are enrolled in Part C services under the category of "Hearing Impairment, Significant Progressive".

Hospital screeners were requested to provide primary care provider (PCP) information for documentation of a medical home; however data entry has not been consistent among the facilities. When the legislation goes into effect in January 2008, it will require all facilities to enter this information in the database. In Alaska, it is important to note, a medical home is not limited to a physician, but may be a public health nurse, a nurse practitioner, a physician's assistant or even a community health aide or practitioner. Rural clinics are often staffed by these mid-level practitioners.

In 2003, the State EHDI Program surveyed audiologists statewide to identify the type and availability of audiology diagnostic services for infants. At that time, survey results indicated pediatric audiology services were available in only 10 Alaskan communities, most of which are urban centers or located in "hub" communities in rural and remote areas. Hub communities are those centers of commerce where rural and remote village residents shop, bank, and seek professional and medical services. In 2007, a follow-up email survey of audiologists in Alaska indicates there are audiologists currently located in nine communities in Alaska; four of these providers are in private practice and the other five see specific populations – either Indian Health Service beneficiaries or military personnel and their dependents. Of the four groups in private practice, two are located in Anchorage, one in Juneau and one in Fairbanks. The Anchorage group provides itinerant services to communities without a resident audiologist and the audiologist in Juneau travels to other communities in Southeast Alaska. Five audiologists provide brainstem auditory evoked response (BAER) diagnostic hearing tests, with only three locations, all located in Anchorage, capable of sedation. The audiologists also identified otolaryngology (ENT) coverage as an issue effecting access to sedated BAERs. Either ENT coverage is not consistently available, as indicated by military audiology in Fairbanks and Anchorage, or there is a two month wait for an appointment at the private facility in Anchorage, a concern raised by audiologists in private practice. This impacts timely clinical follow-up and diagnosis, however the audiologists mentioned above are all working with their facilities on plans to remedy this problem.

Family support and active family participation in the EHDI Program has been ongoing since 2002 when the Family Support Group was organized to serve as a review team for educational materials being developed by the EHDI Program. Upon completion of the review and printing of brochures and manuals for parents, the group discussed options for providing parent support to families of children with hearing loss. To assist with identifying a better vision and focus the group requested assistance from an already well established statewide parent organization in Alaska, the Stone Soup Group (SSG). In November 2006 the EHDI Program implemented a contract with the Stone Soup Group to provide Parent Navigation services to parents of infants/children identified with hearing loss or those who need assistance to navigate the EHDI system, starting at the time of a hearing screening refer. The Parent Navigator is a member of

the EHDI Advisory Committee and provides a report at each meeting. The parent navigation report is used to identify system issues and barriers to meeting the National EHDI 1-3-6 Goals. From January through September of 2007, the Parent Navigator had contact with 61 families located in 24 communities throughout the State; many of these families reside in very rural/remote locations. The Parent Navigator will work with the EHDI Program Manager and EHDI Advisory Committee to identify and facilitate opportunities for parent to parent support in Alaska.

The focus of this project is to ensure that after newborn hearing screening, all infants receive timely clinical follow-up, referral, diagnosis and intervention and parents are informed decision makers throughout this process. (*Healthy People 2010* Goal One: Improve Access to Comprehensive, High-Quality Health Care Services, 2000.) Components of the intended project include: (1) identify children lost to follow-up or lost to documentation through analysis of the data entered in the State's EHDI database, (2) ensure audiological evaluation by three months of age, (3) link to a medical home, (4) enrollment in treatment and early intervention services by six months of age, (5) offer family support services to all families of infants/children with a hearing loss and, (6) establish a system of coordinated services including the child's medical home, family support services, and state and community-based resources in a culturally and linguistically competent manner. (*Healthy People 2010* Goal Eleven: Use Communication Strategies to Improve Health, 2000.)

PROJECT METHODOLOGY/GOALS AND OBJECTIVES

Goal 1: To identify children lost to follow-up as indicated by the State EHDI database and develop a system to track these children to ensure they are rescreened and referred for timely diagnostic evaluation, treatment, and early intervention services.

1.1 By the end of 2008, the EHDI Program will conduct focused database training with all the birthing facilities and public health centers with an emphasis on consistent and accurate data entry.

1.2 By the end of 2008, the EHDI Program will conduct focused database training for audiologists with an emphasis on consistent and accurate data entry of the audiological evaluation and diagnostic process.

1.3 By the end of 2008, the EHDI Program will develop a procedure for ongoing internal surveillance of children lost to follow-up or who missed their newborn screen.

1.4. By the end of 2008, the EHDI Program will develop a Memorandum of Agreement (MOA) with the Early Intervention/Infant Learning Program (EI/ILP) to match children identified in the EI/ILP database with children in the State EHDI database.

1.5 By the end of 2008, the EHDI Program will develop a system for matching the Newborn Metabolic Screening entries with the Newborn Hearing Screening entries to identify children who missed their newborn hearing screen.

Consistent and accurate data enhances the capacity of the State EHDI Program to accurately follow the infant's journey and analyze if the process is meeting the National 1-3-6 goals. Through analysis of the database for consistent data entry, the EHDI staff will take a proactive approach to identifying which children are lost to follow-up versus lost to documentation. As data is entered into a web-based data system at twenty-one birthing hospitals and eight public health centers throughout Alaska, it is essential to have a consistent system for data entry. High staff turnover throughout the State requires ongoing contact on the part of the EHDI Manager with hearing screeners. This goal of consistent and accurate data entry -- both for initial screening and rescreening results --will be achieved through face to face training, quarterly data teleconferences, and quarterly practice profile letters. The EHDI Program will continue to hold trainings on data entry for new hearing screeners as needed.

To achieve greater consistency and accuracy in data entry, advanced training with on-site technical assistance from OZ, will be held in Anchorage for all birthing hospitals and public health nursing centers that provide hearing screens. In addition, the EHDI Program Manager will conduct site visits in Bethel, Fairbanks and Southeast Alaska, and other locations as necessary, to meet with hearing screeners and other members of the EHDI system (i.e. public health nursing, primary care providers, audiology, and early intervention staff) to solve data entry and referral issues.

The State EHDI Program will continue to hold quarterly data teleconferences to reinforce information presented at the database training and to address issues raised by hearing screeners. A representative from OZ Data Systems is present on the teleconferences and minutes are sent to hearing screeners and data entry staff from all facilities and Public Health Centers.

A critical element to determine loss to follow-up is accurate entry of data into the EHDI database by audiologists. This information is essential to verify infants received appropriate and timely diagnostic evaluation after an infant has a failed hearing screening. The audiologist is also an important link to the primary care provider and referrals for early intervention services and family support. Initial training of audiologists was conducted in 2005; however it was not until a refresher training in 2007 that audiologists began to use the database. The State EHDI Program has provided ongoing information to the audiology community that this is a requirement of the Alaska mandate beginning January 2008. A database user group will be established by OZ Systems to improve and simplify data entry for audiologists. Follow-up training for audiologists will be scheduled in Anchorage to improve consistency in data entry.

The National Initiative for Children's Healthcare Quality (NICHQ) model for improvement utilizing the "Plan-Do-Study-Act" (PDSA) cycle will be developed to determine if the database trainings influence the rate of children lost to follow-up vs. lost to documentation for a particular hospital. Along with the quarterly practice profile, the hospital will be sent a list of children identified as missing their newborn screening or needing follow-up for a failed screen on a quarterly basis. The hospital will check this list against their records, determining if the family and the child's primary care provider were contacted and notified of screening results. This project will initially be implemented in a hospital with a strong birth screening program and a known commitment to follow-up. Change in lost to follow-up rate will be followed on a monthly basis. This rate of change will be monitored during the quality improvement project period, and also compared to the hospital's previous rate during the same time period for the previous year.

A second model for improvement using the PDSA Cycle to decrease the number of children lost to follow-up will involve a fax-back system between to the infant's primary care provider and the State EHDI Program. The EHDI Health Program Associate (HPA) will prepare a weekly report of infants/children with a failed screening by facility and the report will be faxed to the primary care provider of record. If a fax is not returned to the EHDI office with documentation on follow-up screening, the EHDI Program Manager will contact the office of the primary care provider by telephone to determine the status of follow-up.

Another critical element to identifying infants/children lost to follow-up is to improve collaboration and establish a MOA, with the State's EI/ILP Program. EI/ILP resides in a different division than EHDI Program within the Department of Health and Social Services. Intervention services are provided by 17 grantees, located in non-profit agencies throughout the State of Alaska. The Consultation and Education for Early Hearing Impairment (CEEHI) Program provides educational consultation to the grantees. The CEEHI Program is located in Anchorage and their staff, educators with a specialty in working with infants/children who are deaf or hard of hearing, provide itinerant services throughout Alaska.

Developing a MOA will be the first step in implementing a system for release of information to the State EHDI Program. This release of information will satisfy FERPA/HIPAA requirements. Upon first contact with EI/ILP, parents will be asked to sign a consent form for data sharing. This will allow a match of children who are identified with hearing loss and are enrolled in early intervention services, with entries in the State EHDI database. Through this match, the State EHDI Program will also identify children with a hearing loss who are not enrolled in EI/ILP. The EHDI Program manager will contact those families to ensure they are informed of service options and opportunities for parent to parent contact. The State EHDI Program can also match this information with audiology data to determine the length of time from diagnosis to enrollment in early intervention services.

Finally, a third model for improvement involves matching weekly birth lists faxed to the State to the hearing screening data entered by the birthing facilities. Currently, this birth list is matched against the list of children with metabolic screening specimens sent to the Oregon Public Health

Laboratory to ensure that all infants are receiving a metabolic screen. This matching system will be modified and used to track and follow-up both screening programs using the OZ Systems database once the metabolic data integration is in place.

Goal 2: To establish a system of care connecting all components of the EHDI community to ensure infants with a refer on newborn hearing screening are not lost to follow-up through improved communication protocols.

2.1 By the end of 2008, each birthing facility's current communication protocol regarding screening outcomes and plan of care for parents will be compared with current EHDI recommendations.

2.2 By the end of 2008, the EHDI Program will facilitate the development of a consistent system for communication between the birthing facility and the primary care providers.

2.3 By the beginning of 2009, the EHDI Program will facilitate the development of a communication system among the audiologists, primary care providers, EI/ILP Programs, and other service programs.

2.4 By the end of 2009, the EHDI Program will develop a communication system for parents and referral sources.

The State of Alaska's Newborn Hearing Screening regulations require hearing screeners to have a communication system for notifying parents and primary care providers of the results of the hearing screening. The EHDI Program staff will contact all birth screen providers for an account of how they transmit screening outcome information to families and primary care providers. The EHDI Program staff will work with hearing screen providers to improve their existing system and meet State EHDI regulations. A model for improvement, using the PDSA Cycle will be developed to test the hearing screen provider's system and compare the rate of loss to follow-up on a quarterly basis. As a second facet of this model for improvement, a survey will be developed to determine if primary care providers know where to look for the results of birth screening.

The pediatric audiology group in Anchorage, that also serves outlying communities, is interested in testing a fax-back system to improve communication among audiology, the primary care

provider and early intervention. A copy of the fax will be sent to the State EHDI Program to check the communication against the data in the data base. This quality improvement model will provide information on successful follow-up to audiology, consistent with EHDI 1-3-6 National Goals.

The Intervention Task Force, a subcommittee of the EHDI Advisory Committee, identified will develop a communication protocol between parents and referral sources. This protocol will ensure that parents are kept in the loop at all times and communication with all referral sources is up to date. The EHDI program promotes parents as decision makers in their child's care. Communication with referral sources is one of the keys of success to achieving a family centered system of care. The Intervention Task Force will present the protocol to the EHDI Advisory Committee for adoption by all participants. The EHDI Advisory Committee will continue to hold meetings three times a year to evaluate the communications protocol and provide feedback on the process established.
The effectiveness of the communication protocol will be measured matching the fax-back system with primary care providers with data in the EHDI database.

The protocol will be presented at Grand Rounds by the AAP Chapter Champion to emphasize the role of the medical home in the EHDI process. In addition to the AAP Chapter Champion, the EHDI Advisory Committee includes the following members: parents, audiologists, hospital birth screeners, Early Intervention/Part C Program Manager; speech language therapists, educators, primary care providers, public health nurses and otolaryngologists. All EHDI members will be encouraged to utilize the protocol for a seamless referral system.

Goal 3: Enhance family support to families of children requiring diagnosis and intervention services by assisting their navigation through the EHDI system

3.1 By the end of 2008, the EHDI Program will promote the role of the parent navigator as a support to parents throughout the EHDI process

3.2 By beginning of 2009, the EHDI Program will identify barriers to parent support and methods by which parents prefer to receive support and information.

3.3 By 2010, the EHDI Program will collaborate with the Stone Soup Group to establish a database for the purposes of parent to parent match

The EHDI Program implemented a contract for parent navigation services with the Stone Soup Group in November 2006. The Stone Soup Group is a parent organization that supports families caring for children with special needs. Stone Soup was recently awarded funding as Alaska's Parent Training and Information Center (PTI). The PTI has training centers fostering collaboration with education and multiple community services in various regions of the State. The many collaborative partnerships of Stone Soup Group, including parent navigation to the Providence Pediatric Neurodevelopmental Clinic and the Neonatal Intensive Care (NICU) developmental follow-up program, provide opportunities for identifying parents in need of parent support, assistance with navigating the system of services, and information. The Parent Navigator is a member of and provides a report to the EHDI Advisory Committee and as well as monthly reports to the State EHDI Program. The parent navigation report will be used to identify systems issues and barriers to meeting the National 1-3-6 Goals, and a springboard for developing future quality improvement projects.

A brochure was developed to introduce parent navigation services. It will be distributed to all EI/ILP grantees. In addition, the AAP Chapter Champion will introduce the role of the Parent Navigator to primary care providers at Grand Rounds.

The Parent Navigator will work with the EHDI Program Manager to develop a survey to determine the method in which parents would like to receive parent support. The survey will look at creative opportunities for parents to communicate and receive information, such as through the internet, web cams, and the traditional parent support meeting. The EHDI Program Manager will analyze identified barriers to parent support and how they may be overcome to ensure families have access to parent support and unbiased information to become informed decision makers. The role of parent navigation will also be promoted throughout EI/ILP as a mechanism for enhancing care coordination for families.

The information from the survey will be used to develop a State Plan to address family support issues. A team of providers and parents will be identified to attend the Annual Investing in Family Support Conference sponsored by National Center for Hearing and Assessment Management (NCHAM). This is an opportunity to hear how other States are supporting families and further enhance the Alaska State Plan.

The EHDI Program Manager will continue to conduct site visits with the parent navigator throughout the State to promote the role of parent navigation with birth screeners, early intervention, public health nurses and primary care providers. In addition the parent navigator will travel with the Assistive Technology for Alaskans (ATLA) to sites in various regions of the state. ATLA will have demonstration sites where parents and providers can view and borrow assistive technology for children who are hard of hearing or deaf. This is another opportunity for the parent navigator to meet parents and develop a parent network. Focus groups will be held to identify how parents would like to receive information and support.

As the Parent Navigator increases contact with families these contacts, with parental consent, will be entered in a database for the purposes of parent to parent match. Parent contacts will also be matched with the EHDI database for completeness of data information as a quality assurance measure. A survey will be developed to assess the usefulness of the parent matching service.

Goal 4: To identify infants/children with high risk factors, late onset or progressive hearing loss to prevent loss to follow-up.

4.1 By the end of 2008, the EHDI Intervention Task Force on Late Onset/Progressive Hearing Loss, will modify the Alaska EHDI Protocol in accordance with the 2007 Joint Commission on Infant Hearing (JCIH) Guidelines.

4.2 By 2009, the EHDI Program will establish a process for integrating children identified late with hearing loss into the EHDI data system.

4.3 By 2009, the EHDI Program will establish a process to integrate children with late onset hearing loss enrolled in EI/ILP and hearing resources into the EHDI system.

4.4 By 2009, the EHDI Program will provide ongoing support to Early Headstart Programs enrolled in the Early Childhood Hearing Outreach (ECHO) Project to identify and report children with high risk factors that may be lost to follow-up.
4.4 By 2010, the EHDI Program will design a pilot project in the Yukon Kuskokwim (YK) Delta region to screen children at risk for hearing loss.

The Early Intervention Task Force, a sub-committee of the EHDI Advisory Committee, met in March of 2007 and reviewed the State EHDI protocol originally developed in 2002. Members of the Task Force, comprised of audiologists, a parent and a representative from the State EI/ILP, recognized a need to update the protocol to address infants/children with late onset/progressive hearing loss and to reflect current best practice as outlined by JCIH. Once this section of the protocol is completed, it will be reviewed by the EHDI Advisory Committee and incorporated into the EHDI communication protocol. It will be disseminated by the State EHDI Program to all components of the EHDI community and introduced at Grand Rounds by the AAP Chapter Champion as well as through other presentations around the State. As a feedback loop, children identified by audiology assessment with late onset and progressive hearing loss will be matched to their newborn hearing screen in the EHDI database.

EI/ILP Programs at various locations throughout the State are screening children birth to three using Otoacoustic Emission (OAE) screeners. A Memorandum of Agreement will be developed for the purpose of obtaining releases and reporting children who do not pass their OAE screening to the State EHDI Program. The screening results will be matched to the child's newborn hearing screening. This will indicate if the child has a late onset hearing loss or was lost to follow-up after a failed newborn screening. Implementation of this process will ensure all children who are at risk or have a confirmed hearing loss are integrated into the EHDI system and receive appropriate audiology and EI/ILP services.

The EHDI Program is participating in the Early Childhood Hearing Outreach (ECHO) Program through Utah State University. Otoacoustic emission (OAE) equipment, purchased by the State EHDI Program, is currently placed in three Early Head Start (EHS) Programs. One EHS Program is located in Anchorage and the other two are in the Interior of Alaska – Fairbanks and

Fort Yukon. The Fort Yukon program serves a remote, rural region of the State. The village of Fort Yukon, and the smaller villages it serves, are accessible only by plane or snow machine. All these programs serve Alaska Native populations. Implementation of OAE screening will promote early identification of children with risk factors for hearing loss which include a high rate of otitis media. The EHDI Program Manager is the point of contact for these programs and facilitates technical assistance for ongoing training and referral information. A process will be developed to incorporate the names of children with a refer on OAE screening into the EHDI database. These children will be matched with their newborn hearing screening record to determine if the child had a failed newborn screening or if this is a late or progressive hearing loss. System issues related to meeting the National 1-3-6 goals may also emerge when this population is entered into the database. The EHDI Program Manager plans to hold quarter teleconferences with the ECHO screeners to include them in the State EHDI Program and ensure infants/children in EHS have timely diagnosis and early intervention services.

The Yukon-Kuskokwim Delta Region is an underserved rural/remote region of the State whose children are at high risk for hearing loss. This region has had inconsistent audiology coverage since 2005. The EHDI Program Manager will work with the audiologist and otolaryngologist at the Alaska Native Tribal Health Consortium (ANTHC) and the Director of the Community Health Aide Program to replicate the ECHO Program in this region. A pilot program will be developed at a Sub-regional Health Center, located in a remote region of the state not accessible by road, to promote OAE screening for all preschool children who receive their medical care at the Sub-Regional Health Center. The EHDI Manager will work with the above partners to train the community health aides/practitioners (CHA/P's) on use of the OAE equipment using the ECHO Project Training Manual and the CHA/P's will be invited to participate in the ECHO teleconferences. An MOA will be developed among all parties. Options for use of telemedicine, between the Sub-regional Health Center and ANTHC located in Anchorage, for consultation and treatment will be explored. Children who do not pass OAE screening will be reported to the State EHDI database and matched to the newborn hearing screening, as well as integrated into the EHDI system.

Goal 5: To ensure all children born outside of birthing hospitals receive newborn hearing screenings.

5.1 By the beginning of 2008, the EHDI Program will update and distribute cards with locations of birth screening facilities to all birthing centers and public health centers through out the State of Alaska.

5.2 By the end of 2008, the EHDI Program will educate birthing center midwives and primary care providers who care for newborns, on the modified EHDI protocol.

5.3 By the beginning of 2009, the EHDI Program will collaborate with the Bureau of Vital Statistics to receive monthly lists of children born outside of hospitals in order to follow-up on their hearing screening status.

5.4 By early 2010, the EHDI Program will develop and distribute a joint newsletter with the Newborn Metabolic Screening Program on a quarterly basis to all primary care providers (including midwives, nurse practitioners, and community health aides/practitioners) that provides information on number of screens, missed infants, where to go for screening, and any important updates.

In the State of Alaska, approximately 4.6% of infants are born outside of birthing hospitals either in private homes or free standing birthing centers. Screening equipment is in place in eight public health centers in communities where there is not a birthing hospital or there is a high rate of out of hospital births. In addition, several birthing hospitals will screen infants born out of hospital for free or a reduced charge as a means to increase access to newborn hearing screening and meet the one month goal of the National 1-3-6 Goals. Cards with the locations for these centers and participating hospitals that can provide screens have been printed. These cards will soon be distributed to providers in the communities listed on the cards. The EHDI Program Manager will continue to distribute these cards at community visits to primary care providers, birthing centers, lay midwives, and early intervention providers. In addition to distributing these cards and EHDI brochures, focus will be placed on educating birthing center staff on the EHDI protocol and their responsibility regarding promoting hearing screening as outlined in their recently established birthing center regulations.

The EHDI Program is developing an agreement with the State Bureau of Vital Statistics to receive a monthly list of children born out of hospitals. This list will be matched with the EHDI database for hearing screening and newborn metabolic screen screening results. Analysis of the data will identify if a particular birthing center requires additional education on the EHDI process or on data entry.

Continuing education to primary care providers throughout Alaska regarding the importance of newborn hearing screening and intervention will be offered at private offices, community and tribal health centers. A joint newborn metabolic screening and newborn hearing screening newsletter will be developed and distributed to midwives, nurse practitioners, and community health aides/practitioners, as a method to convey successes and opportunities for improvement.

WORK PLAN

(See charts on the following pages.)

Work Plan for Implementation of EHDI Goals and Objectives

Goals 1. To identify children lost to follow-up as indicated by the State EHDI database and develop a system to track these children to ensure they are rescreened and referred for timely diagnostic evaluation, treatment, and intervention services. **Healthy People *2010* Targets:** 1) Increase the proportion of newborns who have audiologic evaluation by age three months to 70%. 2) Increase the number of newborns who are enrolled in appropriate intervention services by age 6 months to 85%. **Title V Block Grant Performance Measure** **PM#7** Percentage of newborns who have been screened for hearing before hospital discharge.	**Measures of Success…** 1) Increase the number/percentage of newborns receiving rescreened before hospital discharge or one month of age. 2) Increase the number/percentage of infants/children receiving diagnostic service by 3 months of age. 3) Increase the number/percentage of infants/children receiving Early Intervention/Infant Learning Program (EI/ILP) services by 6 months of age. **Outcome Evaluation Questions:** 1) Are all birth screeners and audiologists entering data in a consistent manner? 2) Are all infants with a failed newborn screening receiving timely follow-up screenings and/or audiology evaluation? 3) Are all infants with hearing loss receiving EI/ILP services in a timely manner? 4) Are primary care providers looking for screening results?

Objectives…	**Activities…**	**Data/Evaluation…**	**Time Frame for Assessing Progress**	**Team Members Responsibilities**
1.1 By the end of 2008, the EHDI Program will conduct focused database training with all the birthing facilities and public health centers with an emphasis on consistent and accurate data entry.	• Schedule an advanced training facilitated by Oz data systems • Arrange for birth screeners and hospital data entry personnel to travel to Anchorage for training • Schedule ongoing training for new birth screeners	• Monitor data received from each facility for accuracy	6/08 and monthly thereafter 6/08; ongoing quarterly	• EHDI Program Manager • EHDI Health Program Associate

	• Conduct quarterly data teleconferences for birth screeners and data entry personnel	• Analyze quarterly practice profiles for each facility • Distribute minutes from quarterly data teleconferences		
1.2 By the end of 2008, the EHDI Program will conduct focused database training for audiologists with an emphasis on consistent and accurate data entry of the audiological evaluation and diagnostic process.	• Schedule an advanced audiology data training facilitated by OZ data systems • Organize an audiology user group facilitated by OZ systems.	• Monitor and analyze data received from audiology. • Audiologists will report on ease of EHDI database usage. • All audiologist will report in the EHDI database	9/08; monthly and ongoing 9/08; Ongoing	• EHDI Program Manager • EHDI Health Program Associate
1.3 By the end of 2008, the EHDI program will develop a procedure for ongoing internal surveillance of children lost to follow-up or who missed their newborn hearing screen.	• Generate weekly reports from the database of children with missed or failed newborn hearing screenings. • Fax report of children needing follow-up to medical home. • Follow-up telephone call to medical home if fax is not returned with documentation. • Generate list of children with missed or failed screen to be	• Develop process into PDSA Cycle to evaluate change in refer rate for specific facilities • Documentation of knowledge of missed screening by medical home • Develop process in PDSA cycle to determine rate of	9/08; ongoing weekly thereafter	• EHDI Program Manager • EHDI Health Program Associate

	mailed with practice profile	change to lost to follow-up		
1.4 By the end of 2008, the EHDI Program will develop a Memorandum of Agreement (MOA) with the Early Intervention/Infant Learning Program (EI/ILP) to match children identified in the EI/ILP database with children in the State EHDI database.	• Develop a MOA with EI/ILP that will satisfy FERPA/HIPPA requirements • Match data between the EHDI Program and EI/ILP • Identify children not in EI/ILP with a diagnosed hearing loss • Contact families not in EI?ILP to ensure they are informed of service options and receiving services.	• Information on children receiving EI services will be transmitted to EHDI • Compare the two program lists to determine the percentage of children receiving intervention services by six months of age • Increase in number of children receiving intervention services by six months of age	9/08; quarterly thereafter	• EHDI Program Manager; • EHDI Program Associate • Part C Program Manager
1.5 By the end of 2008, the EHDI Program will develop a system for matching Newborn Metabolic Screening entries with the Newborn Hearing Screening entries to identify children missed for newborn hearing screen.	• Metabolic screening results will be matched with hearing screening to track children who missed their hearing screening and/or are not entered in the database. • Contact primary care provider with information on children who missed their newborn hearing screening.	• Generate a list of children missing from the EHDI database • Children will receive timely screening.	12/08; ongoing weekly thereafter	• EHDI Program Manager • EHDI Health Program Associate

Work Plan for Implementation of EHDI Goals and Objectives

<table>
<tr><td colspan="2">Goal 2.
To establish a system of care connecting all components of the EHDI community to ensure infants with a refer on newborn hearing screening are not lost to follow-up through improved communication protocols.

Title V Block Grant Performance Measure:
PM #5 Percentage of children with special health care needs age 0 to 18 who report the community based service systems are organized so they can use them easily (CSHCN Survey)

MCHB Discretionary Grant Performance Measures:
PM# 31 The degree to which grantees have assisted States in organizing community-based service systems so that families of children with special health care needs can use them easily</td><td colspan="3">Measures of Success…
1) All birth screeners will have a procedure for notifying parents and primary care providers of birth screening results.
2) The QA project will document the change in the rate of loss to follow-up for screening facilities
3) The EHDI Advisory Committee will adopt the revised protocol.
4) The number/percentage of children meeting 1-3-6 goals will increase.

Outcome Evaluation Questions:
1) Are all components of the EHDI program utilizing the updated EHDI Protocol?
2) Are the results of the QA utilized by birthing hospitals to reduce their rate of loss to follow-up?
3) Are primary care providers utilizing the fax back system to document follow-up?
4) Do parents have documentation of screening results and know “next step”?</td></tr>
<tr><th>Objectives…</th><th>Activities…</th><th>Data/Evaluation…</th><th>Time Frame for Assessing Progress</th><th>Team Members Responsibilities</th></tr>
</table>

2.1 By the end of 2008, each birthing facility's current communication protocol regarding screening outcomes and plan of care for parents will be compared with current EHDI recommendations.	• Contact each birthing facility to document their procedure for notifying primary care providers and parents of screening results	• Each facility will have a system for notifying results of birth screening • A QA project will track the change in rate of loss to follow-up by facility	• 9/08	• EHDI Program Manager
2.2 By the end of 2008, the EHDI Program will facilitate the development of a system for communication between the birthing facility and the primary care providers	• Present protocol to EHDI Advisory Committee for adoption by all participants (including parents, EHDI Chapter Champion, audiology, EI/ILP, physicians, early childhood educators, birth screeners, public health nursing)	• All EHDI members will utilize the communication protocol for a seamless referral system • Increase in numbers meeting 1-3-6 Goals	• 9/08; ongoing monthly thereafter	• EHDI Program Manager; • EHDI Chapter Champion • EHDI Advisory Committee
2.3 By the beginning of 2009, the EHDI Program will facilitate the development of a communication system among the audiologists, primary care providers, EI/ILP programs, and other service programs.	• Present protocol at Grand Rounds sponsored by AAP Chapter Champion • Survey primary care providers to determine if they know where to look for hearing screening results	• Reduction in rate of loss to follow	• 3/09; ongoing	• EHDI Program Manger • EHDI Chapter Champion • EHDI Program Associate

2.4 By the end of 2009, the EHDI Program will develop a communication system for parents and referral sources.	• QA project to determine loss to follow-up for specific facilities • Link communication system to "internal" fax back" process with primary care providers" • Implement a fax-back system between audiology, the primary care provider and early intervention	• Match fax-back information with information in the database for conformity to 1-3-6 National Goals	• 9/09	• EHDI Program Manger • EHDI Program Associate

Goals 3.
Enhance family support to families of children requiring diagnosis and intervention services by assisting their navigation through the EHDI system.
Title V Block Grant Performance Measure:
PM #2: The percentage of children with special health care needs age 0 to 18 years whose families' partner in decision making at all levels and are satisfied with the services they receive. (CSHCN Survey)
MCHB Discretionary Grant Performance Measure:
PM #7 The degree to which MCHB supported programs ensure family participation in program and policy activities.

Measures of Success…
1) Family support will be available to parents at all steps of the EHDI process.
2) Families will have a choice in the manner in which they receive support and information.
3) Family members will participate on all EHDI committees and task forces.

Outcome Evaluation Questions:
1) Were all families of children with hearing loss offered opportunities for parent support?
2) Are all components of the EHDI system familiar with the role of the parent navigator?
3) Was a database established to facilitate "parent to parent" matches?
4) Are family members participants in the EHDI Advisory Committee?

Objectives…	Activities…	Data/Evaluation…	Time Frame for Assessing Progress	Team Members Responsibilities
3.1 By the end of 2008, promote the role of the parent navigator as a support to parents throughout the EHDI process.	• Conduct site visits to introduce the role of the Parent Navigator throughout the State • Distribute brochures on parent navigation to the EI/ILP grantees. • Introduce the Parent navigation process at Grand Rounds.	• Number of families and location accessing parent navigation services reported by Parent Navigator on monthly report • Number of referrals for parent navigation by primary care providers	• 6/08; ongoing monthly thereafter • 9/08; ongoing	• EHDI Program Manager • EHDI Chapter Champion • Parent Navigator
3.2 By the beginning of 2009, the EHDI Program will identify barriers to parent support and methods by which parents prefer to receive support and information.	• Collaborate with the Assistive Technology Library of Alaska (ATLA) to promote parent navigation at assistive technology demonstration sites. • Conduct parent support focus group • Send parent survey • Analyze data from parent navigator reports to EHDI	• Evaluate information from focus group on how parents prefer to receive information and support • Utilize survey, parent navigation reports to identify barriers and generate solutions	9/09 parent survey; ongoing monthly parent navigation reports	• EHDI Program Manager • Parent Navigator • EHDI Program Manager • EHDI Advisory Committee parents
3.3 By 2010, the EHDI	• Organize a team to attend the Annual Investing in Family Support Conference • Utilize the parent navigation	• Development of a state plan to address family support issues • Percentage of families	To be determined 01/10; ongoing	• Parent Navigator • EHDI

Program will collaborate with the Stone Soup Group to establish a database for the purposes of parent to parent match	contacts to develop a database of parents interested in meeting other parents. • Connect with audiology and EI/ILP to augment opportunities for parent support, promoted through EI/ILP mechanism for enhancing care coordination for families.	of children who are deaf or hard of hearing requesting a parent match	thereafter	Program Manager • Parent Navigator

Work Plan for Implementation of EHDI Goals and Objectives

Goal 4. **To identify infant/children with high risk factors, late onset or progressive hearing loss to prevent loss to follow-up.** **MCHB Discretionary Grant Performance Measure:** **PM #23** The degree to which grantees have assisted States in increasing the percentage of children who are screened early and continuously for special health care needs and linked to medical homes, appropriate follow-up and early intervention	**Measures of Success…** 1) Children with late onset/progressive hearing loss will be integrated into the EHDI system. 2) The EI and EHDI data will be matched to capture children later identified with hearing loss. 3) Children screened through the ECHO Project will have timely follow-up. **Outcome Evaluation Questions:** 1) Is the EHDI protocol in compliance with 2007 JCIH guidelines? 2) Are children identified after their birth screening receiving timely follow up? 3) Are children identified after birth screening matched in the EHDI database?

Objectives…	**Activities…**	**Data/Evaluation…**	**Time Frame for Assessing Progress**	**Team Members Responsibilities**

4.1 By the end of 2008, the EHDI Intervention Task force on Late Onset/Progressive Hearing Loss will modify the Alaska EHDI protocol in accordance with the 2007 Joint Commission on Infant Hearing (JCIH) Guidelines.	• The Alaska EHDI Task Force will review and analyze the JCIH 2007 Guidelines and update the EHDI protocol developed in 2002.	• Alaska EHDI protocol will be in compliance with 2007 JCIH guidelines	• 12/08	• EHDI Intervention Task Force • EHDI Program Manager
4.2 By 2009, the EHDI Program will establish a process for integrating children identified late with hearing loss into the EHDI data system.	• Update Alaska EHDI protocol to address children identified with late onset or progressive hearing loss.	• Alaska EHDI protocol will address all children with hearing loss in compliance with JCIH Guidelines	• 6/09	• EHDI Intervention Task Force • EHDI Program Manager • EHDI Advisory Committee
4.3 By 2009, the EHDI Program will establish a process to integrate children with late onset hearing loss enrolled in EI/ILP and hearing resources into the EHDI system.	• Develop an MOA with EI/ILP to report children later identified with hearing loss into the EHDI system	• Protocol will be presented to EHDI Advisory Committee for discussion and approval	• 6/09; ongoing	• EHDI Program Manager • Part C, EI/ILP Manager
4.4 By 2009, the EHDI	• Develop a system for Early	• Later identified	• 6/09; ongoing	• EHDI Program Manger

Program will provide ongoing support to Early Headstart Programs enrolled in the Early Childhood Hearing Outreach Program (ECHO) Project to identify and report children with high risk factors that may be lost to follow-up	Head Start Program to report children with refers to the Alaska EHDI Program • Conduct quarterly teleconferences with ECHO screeners	children will be will be integrated into the EHDI database • Children will be matched with their newborn screening entry in the EHDI database for a complete record of the child's journey		• EHDI Health Program Associate
4.5 By 2010, the EHDI Program will design a pilot project in the Yukon Kuskokwim (YK) Delta region to screen children at risk for hearing loss.	• Meet with the Director of the Community Health Aide Program and Sub-regional Health Center Administrator to discuss a hearing screening pilot program. • Develop an MOA with the above parties. • Designate other partners (e.g. Alaska Native Medical Center). • Schedule training on OAE equipment for Community Health Aides involved in pilot program. • Integrate pilot program with EHCO Project.	• Children identified in ECHO Project will be matched with data in Alaska EHDI database and receive appropriate follow-up • All children with refers will have timely follow-up • Children in a designated region of the YK Delta will be screened for hearing loss and receive appropriate follow-up • Children with refers on screening will be reported to the Alaska EHDI database	6/10; ongoing	• EHDI Program Manager

Work Plan for Implementation of EHDI Goals and Objectives

Goal 5. **To ensure all children born outside of birthing hospitals receive newborn hearing screenings.**		**Measures of Success…** 1) Families of infants born outside of birthing hospital will be informed of locations to receive birth screening. 2) Increase the number of newborns screened before one month of age. **Outcome Evaluation Questions:** 1) Are families of all infants born in the State of Alaska given information on newborn hearing screening? 2) Are families of infants born outside of birthing hospitals accessing hearing screenings? 3) Does the community have up to date information on the EHDI Program?		
Objectives…	**Activities…**	**Data/Evaluation…**	**Time Frame for Assessing Progress**	**Team Members Responsibilities**
5.1 By the middle of 2008, the EHDI Program will update and distribute cards with locations of birth hearing screening facilities to all birthing centers and public health centers throughout the State of Alaska.	• Inform all midwives and public health centers of locations to access birth hearing screenings	• Increase in number of infants born out of birthing hospitals receiving newborn hearing screening	• 6/08	• EHDI Program Manager • EHDI Health Program Associate
5.2 By the end of 2008, the EHDI Program will educate birthing center midwives and primary care providers who care for newborns, on the	• Disseminate information on the updated protocol to midwives and primary care providers through conferences, site visits and	• All midwives and primary care providers will be informed of the EHDI system and their patients will have	• 9/08	• EHDI Program Manger

modified EHDI protocol.	mailings	appropriate referrals		
5.3 By 2009, the EHDI Program will collaborate with the Bureau of Vital Statistics to receive monthly lists of children born outside of hospitals in order to follow-up on their hearing screening status.	• Match names received from the Bureau of Vital Statistics to determine if infants have received a hearing screening. • Contact primary care providers of need for screening.	• Compare number of out of hospital births with number of entries in database from out of hospital screenings	• 6/09	• EHDI Program Manager
5.4 By early 2010, the EHDI Program will develop and distribute a joint newsletter with the Newborn Metabolic Screening Program on a quarterly basis to all primary care providers (including midwives, nurse practitioners, and community health aides/practitioners) that provides information on number of screens, missed infants, where to go for screening and any important updates.	• Distribute newsletter to all aspects of the medical community throughout the State of Alaska.	• Medical community will be informed of latest information on newborn screening to meet 1-3-6 goals	03/10	• EHDI Program Manager • Newborn Metabolic Screening Manager

RESOLUTION OF CHALLENGES

Challenge #1: Implementation of the EHDI Program throughout the State of Alaska requires overcoming the obstacles of vast geographic distances, severe climate and sparse populations that reside in isolated villages. It is a challenge to provide follow-up medical care to residents who live in remote regions of the state, where there are often no roads, and villages are accessible only by small plane or boat. The great majority of these villages do not have a resident physician nor a nurse practitioner or physician assistant. A community health aide/practitioner is often the primary care provider for the infant and family. Due to the lack of roads, residents in rural communities rely on air transportation to access larger communities with higher technology.

Possible Resolution: Alaska's involvement with the ECHO Program is a mechanism for reaching children at risk for hearing loss in their home village. The proposed pilot program for the Yukon-Kuskokwim Delta will provide hearing screening to a greatly underserved region. In fact, Bethel the hub community for this region, recently lost its audiologist after serving in the community for six months. Prior to that time, the community was without an audiologist for over a year. Reporting ECHO results to the EHDI Program presents an opportunity to track children who need rescreening or audiology evaluation. Coordination with the Alaska Native Medical Center (the tertiary referral center for the Indian Health Service) in Anchorage is essential for problem solving issues surrounding access to follow-up. The pediatric audiologist and the chief of otolaryngology are active participants on the EHDI Advisory Committee and essential partners to finding creative solutions such as telemedicine.

Challenge #2: Overcoming the HIPAA/FERPA issues regarding data reporting by Early Intervention/Infant Learning Program (EI/ILP) are essential for meeting the National EHDI 1-3-6 Goals.

Possible Resolution: Development of a Memorandum of Agreement (MOA) with the Early Intervention/Infant Learning Program as proposed in this grant is the first step in overcoming this barrier. EI/ILP is located in the Department of Health and Social Services, but resides in a different division, the Office of Children's Services (child protection services). Once an MOA is

in place on the State level, the 17 grantees that implement early intervention programs throughout the State can obtain releases from families to report children with hearing loss to the EHDI program. This will provide information on which children are receiving intervention from EI/ILP when compared with those in the EHDI database. This data match will assist in identifying children lost to follow-up and the State's timeliness in meeting the National EHDI 1-3-6 Goals.

Challenge #3: Staff shortages and staff turnover are a significant ongoing challenge in Alaska. They occur at all levels and impact all components of the EHDI process including: birth screeners, audiologists, early interventionists, speech/language pathologists and physicians. Staff turnover also affects the quality of data entry. Consistency in data entry and weekly reporting are necessary in order for the EHDI Program Manager and EHDI Health Program Associate to follow-up on missed and failed screens.

Possible Resolution: Ongoing training on data entry will improve accuracy of data and opportunities to train new birth screeners. Communication venues are essential to ameliorate the impact of ongoing turnover. Site visits, quarterly teleconferences and practice profiles provide mechanisms for consistency in EHDI data collection and ongoing information on the EHDI process. In addition the EHDI mandate which takes effect January 2008 will require timely reporting by all birthing hospitals, audiologists and EI/ILP.

Challenge #4: Challenges to follow-up occurs in all communities, not just those in rural Alaska. These challenges include how information is relayed to parents and primary care providers regarding missed or failed screens.

Possible Resolution: Solutions supported by this grant will focus on how results are transmitted to primary care providers and parents by birthing hospitals. A model for improvement will address this challenge. In addition, the AAP Chapter Champion will communicate with physicians across the State regarding the responsibility of primary care providers to look for newborn hearing screening results on all infants. The plan to update the EHDI communication

protocol, in accordance with 2007 JCIH guidelines, will outline steps to improve timely follow-up on referrals.

Challenge #5: Avenues for parent to parent support are another ongoing challenge.

Possible Resolution: Various options for offering parent support such as face-to-face meetings, email and web-based chats will be explored through focus groups, parent surveys and Parent Navigator reports. The role of the Stone Soup Group Parent Navigator is an essential component of this process, as well as the input from parents on the EHDI Advisory Committee.

EVALUATION AND TECHNICAL SUPPORT

The EHDI Program resides in the Section of Women's Children's and Family Health in the Division of Public Health (the State's Title V and Children with Special Health Care Needs Agency). The Children's Health Unit is managed by a Health Program Manager III who previously held the title of EHDI Surveillance Manager, and who has several years of experience in working with the EHDI Program. The EHDI Program Manager has extensive experience in the field of Early Intervention/Infant Learning Programs, and understands the principles and the barriers to making this connection work in the EHDI system. The EHDI Program Manager also has previous involvement with a statewide Medical Home Special Projects of Regional and National Significance (SPRANS) Grant in Alaska and will focus on engaging primary care providers in the EHDI Program. The EHDI Program Manager will work with the AAP Chapter Champion, EHDI Advisory Committee, and Parent Navigator to promote and operationalize the Alaska EHDI protocol and achieve the National EHDI 1-3-6 Goals. Funding from this grant is necessary to support this position which is vital to the success of this program.

This year, a Health Program Associate will be added to provide more advanced support and to aid in the data cleaning and analysis from the EHDI database. The Health Program Associate will be responsible for overall database management of OZ Systems database used by the EHDI Program. This position will run data reports, assess quality of data entry and implement quality assurance procedures for accurate data entry. This position will also coordinate with other State

agencies, such as the WIC Program and Medicaid, to locate families to decrease the number of children lost to follow-up. The above positions form a cohesive team to work towards the goals as outlined in this application.

Technical support from OZ Systems and their State Program Coordinator is an asset to achieving data integrity. The State Program Coordinator participates in data teleconferences, provides technical assistance to running reports, and problem solves data entry difficulties with birthing hospitals. OZ initiated and is facilitating a user group for audiologists to simplify the process of entering assessment data by audiology.

Along with staff, a major asset and crucial partner of the Alaska EHDI Program are the dedicated members of the EHDI Advisory Committee. At this time the committee formed a task force to examine the process from diagnosis to early intervention services. A second task force was created to ensure timely follow-up of children with late onset/progressive hearing loss. With the recent release of the 2007 JCIH guidelines the group is proposing the development of a third task force to examine the State Audiological Assessment Guidelines. The work of these three groups will result in an updated communication protocol for the Alaska EHDI Program reflecting the 2007 JCIH Guidelines.

Previously the EHDI Advisory Committee worked with the EHDI Program Manger to produce materials for parents on newborn hearing screening. These materials are now available in six languages English, Spanish, Korean, Hmong, Tagalog and most recently, Russian. These materials are continually distributed throughout the State to engage all parents in the EHDI system.

The EHDI Program has a contract with the Stone Soup Group, a parent organization, to provide parent navigation to families throughout the state. This is achieved through travel, teleconferences, and email. A brochure on parent navigation was developed and is distributed to providers to promote the importance of parent support. The State partnership with the Stone Soup Group strengthens the EHDI system and its belief in parental choice and the families' role as decision makers.

Evaluation of progress on meeting the goals and objectives for this grant will be based on the improvement made in reaching the National EHDI 1-3-6 Goals by analysis of: 1) data entered into the database; 2) satisfaction of families working through the diagnostic, treatment and intervention process as evidenced by surveys, and 3) involving new partners to collaborate with the State EHDI Program.

ORGANIZATIONAL INFORMATION:

The EHDI Program is in the Children's Health Unit within the Section of Women's, Children's, and Family Health (the State's Title V and Children with Special Health Care Needs Agency) whose mission is to promote optimum health outcomes for all Alaskans. This section is one of nine sections in the Division of Public Health (DPH) which resides in the Department of Health and Social Services (HSS). The mission for the DHSS and DPH is "To promote and protect the health and well being of Alaskans".

As detailed in the attached organization chart, the EHDI Program is managed by a Public Health Specialist II with support from an Admin Clerk III. This year a Health Program Associate will be added to provide more advanced support and to aid in the data analysis from the EHDI database. The Children's Health Unit is managed by a Health Program Manager III who manages the Newborn Metabolic Screening (NBMS) Program and oversees the managers of the EHDI Program, and the State sponsored Genetics Clinics. The co-location of these programs in the same unit ensures the success of the EHDI/NBMS data integration project and the ability to track those infants diagnosed with a hearing loss receiving a genetics evaluation. These positions together form a cohesive team committed to working towards the goals as outlined in this application.

Another unit within the Section of Women's, Children's, and Family Health is the Maternal Child Health (MCH) Epidemiology Unit which analyzes programmatic data and produces MCH data books. Recent publications include the "2003 Alaska MCH Data Book", the "2004 PRAMS Edition", and the "2005 Birth Defects Edition". Future publications will contain data analyzed from the EHDI database.

Legislation mandating newborn hearing screening was signed by Alaska's Governor in June 2006 with an effective date of January 1, 2008. The statute was developed based on the AAP model legislation. The statute requires all newborns to have a hearing screening performed by one month of age. Regulations outlining the required elements of the statute have been finalized and are waiting for signature by the Lt. Governor. Provisions in the statute and the regulations address screening, reporting, and connections to audiology and early intervention. All parties involved in this process (screeners, audiologists, and the State EI/ILP program) are required to report to the State either through direct entry into the database or by paper reporting to the EHDI Program. The State has worked with the database contractor (OZ Systems) to have an integrated child health profile in place by the end of 2007 that will integrate newborn hearing screening and newborn metabolic screening. Through this integration, further applications will be considered.