

Reducing Lost to Follow-up After Failure to Pass Newborn Hearing Screening - Alaska

GOAL/AIM I: Ensure all infants discharged from the hospital with a “refer” or missed screen will receive follow-up re-screening by one month of age.

Aim/Objective 1.1: By March 2017, 85% of all newborns who did not pass or who did not receive their newborn hearing screen will have a rescreen and/or audiology appointment by one month of age.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1.1.1 Query the database on a monthly basis to check for missed data by facility and send fax-backs	4/1/2014	Ongoing / Quarterly	Health Program Associate (HPA)	Fax-backs are returned with updated status of children	Increase in percentage of complete or accurate records by facility
1.1.2 Review and formalize EHDI guidelines to maximize use of database hearing reminders for earlier notification to parents and PCP	4/1/2014	7/1/2014	EHDI Program Manager (EHDI PM) HPA Unit Manager	Formalized guidelines are created with stakeholder support and reviewed by advisory committee	# of children that have rescreen, or initial screen, before one month of age
1.1.3 Develop PDSA process to track timeframe for sending letters to parents & faxes to PCP	7/1/2014	12/31/2014	EHDI PM HPA QI Team	Timeliness of notification to parents and PCP is monitored by program staff through weekly database tracking	Reduced number of days between notification and rescreen or audiology appointment
1.1.4 Utilize PDSA process to trial effectiveness of guideline changes	1/1/2015	3/31/2015	EHDI PM HPA QI Team	Changes in guidelines are operationalized	# of children that have rescreen, or initial screen, before one month of age
1.1.5 Develop an online survey to ascertain how birth screeners are employing strategies to	7/1/2014	9/30/2014	EHDI PM HPA	Tabulate the results of the survey	Results of survey will guide future PDSA cycles and effective strategies will be spread

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reduce loss to follow-up					
1.1.6 Using PDSA process, pilot a scripted message for birth screeners at facilities with a high rate of loss to f/u to ensure consistent and accurate information is given to families	7/1/2014	Ongoing	EHDI PM	Change in the rate of loss to f/u will be measured through the PDSA process	Decrease in rate of loss to follow-up by specific facilities
1.1.7 Results of PDSA data will be shared with stakeholders and disseminated as appropriate	1/1/2015	January EHDI Advisory Meeting	EHDI PM HPA	Stakeholders will receive documentation of change in loss to f/u from PDSA process	Change in rate of loss to f/u for identified facilities Change in rate of loss to f/u for all facilities

Aim/Objective 1.2: By March 2017, all birthing facilities in Alaska will have a refer rate of no more than 4%.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1.2.1 The EHDI Program will continue to monitor the refer rate for all birthing facilities and identify those facilities with a refer rate greater than 4%	4/1/2014	Ongoing / Quarterly	EHDI PM HPA	Generate “Practice Profiles” aggregate report and send quarterly to all birthing facilities	Facilities with a refer rate over 4% will receive notification.
1.2.2 Facilities identified with a high refer rate will be contacted and education on EHDI best practice strategies will be provided	4/1/2014	Ongoing / Monthly	EHDI PM HPA	Action plan will be developed with identified facilities using PDSA model	Identified facility will reduce refer rate to \leq 4%
1.2.3 EHDI Program will	4/1/2014	Ongoing /	EHDI PM	Refer rate will be queried	Identified facility will

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continue to analyze data generated on those facilities identified with a high refer rate and provide feedback		Monthly	HPA	in the database for change in refer rate and shared with facilities	reduce refer rate to $\leq 4\%$
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GOAL/AIM 2: Ensure out of hospital births receive newborn hearing screening and appropriate follow-up in accordance with National EHDI 1-3-6 Goals.

Aim/Objective 2.1: By March 2017, the screening rate for out of hospital births (i.e. home births, midwifery centers, etc.) will increase from 70% to 80%.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
2.1.1 Continue quarterly communication with midwives through reports with name and aggregate data on screening rates.	4/1/2014	Ongoing / Quarterly	EHDI PM HPA	Midwives are informed quarterly of screening status for their birth population	Increased screening rate and follow up for OOH births from midwives who receive quarterly reports
2.1.2 Engage parent of child diagnosed with a hearing loss birthed OOH to serve as a parent advocate to promote screening to OOH births	4/1/2014	7/1/2014	EHDI PM Midwifery Center Audiology	Identify parents of children born OOH diagnosed with a hearing loss	Increased screening and follow up rate for OOH births from parents who receive letters from parent advocates
2.1.3 Establish annual telephone calls with midwives who received screening equipment to solicit ideas for improving screening rates	9/1/2014	12/31/2014	EHDI PM HPA	Identify core group of midwives to participate on annual call	Annual call conducted, updates shared and innovate ideas disseminated

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Aim/Objective 2.2 By March 2017, 90% of infants born out of hospital birth will be screened by thirty days.					
Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
2.2.1 Review process for using demographic data from Newborn Metabolic Screening for earlier notification for parents	4/1/2014	Ongoing	HPA	Process for earlier notification will be adopted	OOH births will be screened by 30 days of age
2.2.2 Track screening timeline for OOH births receiving early notice	7/1/2014	Ongoing	HPA OZ Systems	Identify number of screens administered after early notice	OOH births will be screened by 30 days of age
2.2.3 Identify which population is not getting screened	7/1/2014	Ongoing	HPA	Analyze data to target education	Improve screening rate for OOH births by 30 days of age
2.2.4 Develop PDSA for improving screening rate in target population	9/1/2014	Ongoing	EHDI PM HPA QI Team Midwifery Center	Implement strategies	Improve screening rate for OOH births by 30 days of age

GOAL/AIM 3: Ensure infants who do not pass their final hearing screening receive an audiologic assessment no later than 3 months of age in accordance with National EHDI 1-3-6 Goals.

Aim/Objective 3.1: By March 2017, the rate of loss to follow-up between last hearing screen and diagnostic evaluation will be reduced by 50% for private hospitals/birthing centers in Alaska.

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Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
3.1.1 Contact key personnel at private birthing facilities with a high rate of loss to follow-up and identify obstacles for scheduling audiology appointment	4/1/2014	Ongoing	EHDI PM	Barriers to scheduling audiology appointments after a failed screening will be identified by key personnel (Quality Improvement Team)	Quality improvement plan for overcoming obstacles will be developed by key personnel in conjunction with EHDI Advisory Committee
3.1.2 Develop PDSA to improve process for scheduling audiology appointments before hospital discharge	9/1/2014	6/1/2015	EHDI PM HPA	Process for scheduling audiology appointments will be tracked by key personnel (Quality Improvement Team)	Increase in number of audiology appointments scheduled by 3 months of age
3.1.3 Develop standardized protocol for scheduling diagnostic evaluation that reflects information from quality improvement measures	4/1/2015	6/1/2015	EHDI PM EHDI PHS QI Team	Facility adoption of audiology best practice policies as identified by key personnel (Quality Improvement Team)	Increased number of diagnostic evaluations by 3 months of age
3.1.4 Partner with the AAP Chapter Champion on strategies to notify PCP of need for audiology follow-up on patients with a failed screen	9/1/2014	Ongoing	EHDI PM EHDI Advisory EHDI AAP Chapter Champion	AAP Chapter Champion regularly communicates with PCPs to increase awareness of audiology follow-up needs	Informed PCPs ensure audiology appointment is made for children with a failed screen
3.1.5 Develop PDSA to track the outcome of fax-backs sent to PCP's	9/1/2014	12/31/2014	EHDI PM HPA	Track fax-back response to confirm audiology appointments	Increased number of diagnostic evaluations by 3 months of age

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Aim/Objective 3.2: By March 2017, the rate of loss to follow-up between last hearing screen and diagnostic evaluation will be reduced by 50% for children receiving their health care in the native health system.					
Changes / Activities (sequence as needed)	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
3.2.1 Meet with key personnel at Alaska Native Medical Center to draft a protocol for scheduling audiology appointments prior to infants discharged from Anchorage to remote regions of the state	7/1/2014	12/31/2014	EHDI PM Alaska Native Medical Center (ANMC) Team	Process for scheduling audiology appointments after failed rescreen will be identified	Infants will have audiologic evaluation after failed rescreen by 3 months of age
3.2.2 Develop PDSA to track effectiveness of new protocol for scheduling audiology appointments before discharge to rural communities	1/1/2015	6/30/2015	EHDI PM ANMC Team	Process for scheduling audiology appointments will be tracked	Increase in number of audiology appointments scheduled by 3 months of age
3.2.3 Formalize standardized protocol for scheduling diagnostic evaluation that reflects information from quality improvement measures	9/1/2015	12/31/2015	EHDI PM ANMC Team	Process for scheduling audiology appointments after failed rescreen will be formalized	Infants will have audiologic evaluation after failed rescreen by 3 months of age
3.2.4 Meet with audiology department at ANMC, regional birth screeners and PCPs to determine applicability of the newly	1/1/2016	6/30/2016	EHDI PM ANMC Team Regional Birth Screeners	Process for scheduling audiology appointments after failed rescreen will be identified	Infants born at remote facilities will have audiologic evaluation after failed rescreen by 3 months of age

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established protocol for infants born at remote regional facilities who do not pass screening					
3.2.5 Develop a PDSA to trial diagnostic referral process for remote facilities	6/1/2016	12/31/2016	EHDI PM ANMC Team Regional Birth Screeners	Identify key personnel to participate and track PDSA diagnostic referral process for remote facilities	Increased awareness among PCPs of the need for diagnosis by 3 months of age
3.2.6 Modify, if applicable, and formalize standardized protocol to ensure early diagnostics for infants born in remote locations	1/1/2017	3/31/2017	EHDI PM ANMC Team Regional Birth Screeners	Process for scheduling audiology appointments after failed rescreen will be formalized	Infants born at remote facilities will have audiologic evaluation after failed rescreen by 3 months of age
3.2.7 Meet with key stakeholders in the native health system to explore feasibility of tele-audiology for diagnostics in rural remote communities	1/1/2015	Ongoing	EHDI PM ANMC Team	Identify key personnel and critical remote locations for assessing tele-audiology trials	Capacity for remote tele-audiology diagnostics will be determined

Aim/Objective 3.3: By March 2017 the rate of loss to follow-up between last hearing screen and diagnostic evaluation will be reduced by 50% for children receiving their health care in the military system.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
3.3.1 Contact key personnel at the two military bases and identify	4/1/2014	Ongoing	EHDI PM Military Staff	Barriers to scheduling audiology appointments after a failed screening	Plan for overcoming obstacles will be developed

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barriers for scheduling audiology appointments and make a plan for overcoming obstacles				will be identified	
3.3.2 Develop PDSA to evaluate plan for scheduling audiology appointments before hospital discharge	1/1/2015	06/30/2015	EHDI PM Military Staff QI Team	Process for scheduling audiology appointments will be tracked	Increase in number of audiology appointments scheduled by 3 months of age
3.3.3 Develop standardized protocol for scheduling diagnostic evaluation that reflects information from quality improvement measures	9/1/2015	9/30/2015	EHDI PM Military Staff QI Team	Process for scheduling audiology appointments after failed rescreen will be formalized	Formalized protocol for scheduling audiology appointments after failed rescreen
3.3.4 Work with military personnel to have improvements adopted as part of mandatory compliance manual	12/1/2015	6/30/2016	EHDI PM Military Staff	Key military personnel work with EDHI to develop standardized policies for inclusion in accordance with best practice	Standardized protocol will be included as part of mandatory compliance manual

AIM/GOAL 4: Ensure infants/children diagnosed with a hearing loss receive seamless services from diagnosis through intervention and are offered family support

Aim/Objective 4.1: By March 31, 2017 the EHDI Program will increase the number of children enrolled in EI/ILP Part C by 6 months of age from 44% to 75%.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
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4.1.1 Provide education on referral process to early intervention to all audiologists	12/1/2014	Ongoing	EHDI PM EI/ILP	Early Intervention staff conduct education to Advisory Committee; additional materials shared electronically or via teleconference	Increased knowledge among audiologists regarding Early Intervention
4.1.2 Meet with EI/ILP staff and review and revise 2008 MOA with EHDI	9/1/2014	12/31/2014	EHDI PM EI/ILP	EI/ILP staff are aware and knowledgeable of EDHI goals and partnership strategies	Revised MOA that incorporates a streamlined EI referral process for obtaining consent for release of information
4.1.3 Identify gaps and barriers to enrollment in EI services	1/1/2015	Ongoing	EHDI PM EI/ILP QI Team Parent Navigator	Increased awareness among stakeholders on the critical need for seamless enrollment in services	Increased, timely enrollment in Early Intervention
4.1.4 Develop PDSA for obtaining timely release of information from EI to EHDI	4/1/2015	9/1/2015	EHDI PM EI/ILP Parent Navigator	Track improvement in timely enrollment in EHDI database	Increased, timely enrollment in Early Intervention
4.1.5 Pilot PDSA process with next cohort of infants diagnosed with hearing loss	9/1/2015	12/31/2015	EHDI PM EI/ILP	Enrollment in Early Intervention will be tracked through the EDHI database	Increased, timely enrollment in Early Intervention
4.1.6 Evaluate pilot, standardize process for all infants diagnosed with hearing loss	12/1/2015	3/31/2016	EHDI PM EI/ILP QI Team	Standardized protocol for enrollment will be disseminated to all EI/ILP grantees	Increased, timely enrollment in Early Intervention

Aim/Objective 4.2: By March 2017, 100% of all parents of children diagnosed with a hearing loss will be offered family support through parent navigation services.

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4.2.1 Meet with Stone Soup Group (SSG) and review baseline for family support services	7/1/2014	9/30/2014	EHDI PM Parent Navigator	Document meetings through minutes	Enhanced parent support protocol
4.2.2 Provide education to providers on role of parent support to improve loss to follow-up	4/1/2014	Ongoing	EHDI PM	Stakeholders report awareness of SSG’s existing parent navigation services	Stakeholders will utilize SSG to support families who might otherwise be LTF
4.4.3 Conduct and analyze parent satisfaction survey and include questions on cultural competency and identify methods by which parents prefer to receive support and information	7/1/2015	9/30/2015	EHDI PM MCHB Intern MCH EPI PM	Identify or develop parent satisfaction survey with feedback from stakeholders	Results from parent satisfaction survey will be disseminated and utilized to improve services
4.2.4 Partner with the Alaska Native Tribal Health Consortium and Stone Soup Group to explore options for providing parent support in rural communities	9/1/2015	Ongoing	EHDI PM Parent Navigator ANTHC	Explore options for cultural and linguistic competency given the low incidence of hearing loss	Enhanced, culturally competent parent services in remote communities
4.2.5 Explore opportunities for monthly telephonic parent support group	9/1/2015	Ongoing	EHDI PM Parent Navigator EHDI Advisory Committee	Include query around feasibility of telephonic parental support group in parent service survey	Disseminate results of survey to SSG to improve existing parental support networks

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AIM/GOAL 5: Establish a system of care connecting the EHDI Program with community partners who work with families of young children to ensure children are not lost to follow-up

Aim/Objective: By June 2015, the EHDI Program will re-establish a core team with a focus on quality improvement strategies to decrease loss to follow-up.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
5.1.1 A core team representing birth screeners, audiologists, pediatric specialists and early interventionists will set up a regular schedule to initiate and review QI projects	4/1/2014	Monthly Ongoing Meeting	EHDI PM QI Team	New PDSAs will be initiated	QI project results will be assessed, adopted or abandoned
5.1.2 Core team will review CDC’s “What audiologists want parents to know” checklist along with 2011 NICHQ checklist	9/1/2014	12/31/2014	EHDI PM QI Team Audiology	Audiology practices will be designated to trial CDC and NICHQ checklists	Checklists will be adopted/adapted and disseminated to audiology practices statewide

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Objective 5.2: By March 2015, the EHDI Program will increase the knowledge of newborn hearing screening to programs working with young children.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
5.2.1 The EHDI Program will contact all home visitation programs to offer education and technical assistance on the National 1-3-6 Goals	12/31/2014	3/30/2015	EHDI PM Home Visitation Program	Identification of home visitation programs across Alaska, increased communication between these programs and EDHI staff	Enhanced understanding and operationalization of National 1-3-6 Goals among home visitation programs across Alaska
5.2.2 The EHDI Program will contact early childhood programs such as Early Head Start and Parents as Teachers to support screening activities and educational needs	12/31/2014	3/30/2015	EHDI PM Early Head Start Parents as Teachers	Identification of early childhood programs across Alaska, increased communication between these programs and EDHI staff	Enhanced understanding and operationalization of National 1-3-6 Goals among early childhood programs across Alaska

Aim/Objective 5.3: By March 2015, the EHDI Program will collaborate with community partners on strategies to decrease loss to follow-up.

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Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
5.3.1 The EHDI Program will meet with the immunization program to explore opportunities to reach “hesitant” populations	9/1/2015	Ongoing	EHDI PM Alaska Immunization Program	Identify feasibility of a “match” among parents who are vaccine hesitant and those who do not follow up post-screening	Decrease LTF among “hesitant” populations
5.3.2 Redistribute the “Sounds and Silence” Video to community health aids in the native health system	9/1/2014	Ongoing	EHDI PM HPA	Increased knowledge among community health aides of newborn hearing screening and risk of hearing loss	Increased referrals for follow up among community health aides
5.3.3 The EHDI AAP Chapter Champion will work with the QI team to explore opportunities for distribution of Just in Time materials to health care providers	1/1/2014	Ongoing	EHDI PM AAP Chapter Champion	“Just in Time” trainings will be trialed with health care providers through the EHDI/AAP networks	Increased education among health care providers of newborn hearing screening and risk of hearing loss

Alaska Early Hearing Detection and Intervention Project Proposal 2014-2017

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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 newborn hearing screening with the goal of reducing the rate of loss to follow-up by 20% by March 2017. Continuation of federal funding in support of Universal Newborn Hearing Screening and Intervention (UNHSI) in Alaska will ensure that early identification through screening, connection with diagnostic and treatment services, early intervention and family support are a well-functioning system of care for all Alaskan children with hearing loss.

Background

Alaska is the largest of the 50 states, and is one-fifth the size of the continental United States with 586,412 square miles of land. It has 640 square miles of land for every mile of road compared to Texas, which has 20 square miles for every mile of road. Approximately 75% of Alaskan communities, including the state's capital city of Juneau, are not connected to the road system. Accessing "nearby health services" or specialized health care means travel by commercial jet, small plane, the state marine ferry system, all-terrain vehicles, small boats or snow machines. Some residents may travel distances equivalent to traveling from Washington, D.C. to New Orleans for even routine medical care. Moreover, severe weather can render travel impossible, creating especially critical situations in medical emergencies

To address geographic and health care challenges, Alaska has built the infrastructure and a state-wide system to support the National 1-3-6 Goals, of screening before hospital discharge or by one month of age, audiologic assessment for infants that do not pass screening by three months of age and enrollment in early intervention by six months for children with a diagnosed hearing loss. When Alaska received federal funding to implement the Early Hearing Detection and Intervention Program through the Alaska Department of Health and Social Services in 2000, the hearing screening rate for infants discharged from the hospital was 60%. As of 2012 the screening, rate for hospital discharge is 99%. The screening rate for out of hospital births has increased from 38% in 2009 to 60% in 2011 and is projected to be 70% in 2012. The combined screening rate for all occurrent births reported to the CDC in 2011 was 96.7%.

While continuing to support birth screeners throughout the state, the focus of Alaska's EHDI Program shifted to reducing the number of children lost to follow-up after screening and earlier access to diagnostic audiology, intervention services and parent support. In CY2010 the state reported a loss to follow-up/loss to documentation rate of 74.3%; in CY 2011 this rate reduced to 44.7%. Alaska is committed to employing quality improvement strategies to continue to reduce the rate of loss to follow-up by a minimum of 5% per/year between 2014 and 2017.

Legislation

Alaska legislation mandating newborn hearing screening was passed into law in May 2006 and the statute and accompanying regulations took effect January 2008. This legislation follows the National EHDI 1-3-6 goal of newborn hearing screening prior to hospital discharge or by one month of age, audiologic assessment for newborns that did not pass their screening by three

months of age and intervention services for children diagnosed with a hearing loss by 6 months of age. The mandate requires all birthing hospitals and audiologists to report screening and assessment results to the State's EHDI web-based database. It also requires the Bureau of Vital Statistics (BVS) to provide EHDI with a list of all parents born out of hospital and the EHDI Program to notify those parents of the benefits of newborn hearing screening; this population represents 6% of yearly births in Alaska.

Web-based Tracking and Surveillance System

To track Alaskan infants across vast regions of the State and reduce loss to follow-up after newborn screening, the State of Alaska has contracted with Optimization Zorn Corporation (OZ Systems) of Arlington Texas since 2005 to implement a web-based data system. The AKEHDI database has the capacity to accurately collect, match and report unduplicated and individually identifiable data on all occurrent births. All birth screening facilities, which include twenty birthing hospitals, three public health centers and four midwifery centers are required to enter demographics and birth screening results into the database on a weekly basis. Audiologic assessment data is entered and report monthly. OZ Systems can also track early intervention enrollment and family support referrals. In 2008, OZ systems integrated the EHDI with Newborn Metabolic Screening (NBMS) for a complete record of infant screening. This integration provides EHDI with the name of the primary care provider (PCP) reported on the blood spot card. It also provides a name match between the two programs as a tracking for missed infants. Since Alaska does not have an electronic birth certificate that pre-populates the database, the integration of these two data systems records information that would not otherwise be easily accessed. The database is a vital component for identifying children lost to follow-up by region, hospital and other factors. It provides the data reported on the annual CDC data survey. The reports generated from the database are the foundation for the state's fax-back system and communication with births screening facilities, primary care providers (PCPs) and audiologists. The data extracted from the database drives strategies for change and measures the success of those strategies.

Stakeholders

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 actively promote the EHDI 1-3-6 National Goals in Alaska. The Advisory Committee representation on the committee was chosen to represent all facets of the program, including those that represent diverse populations, professions, parents, consumers and the American Academy of Pediatrics (AAP) EHDI Chapter Champion. In this forum, challenges and barriers to services are identified as well as areas in which technical assistance from 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 have generated proposals for models for quality improvement.

The Alaska EHDI Program believes that parent input throughout the EHDI process is essential for a strong program that is responsive to the needs of parents of infants/children with hearing loss and will assist in reducing loss to follow-up. Parent representation is sought for all EHDI committees and the State continues to fund parent navigation services through Stone Soup Group, a parent advocacy organization for children with special health care needs. Opportunities

for joining a national organization such as Hands and Voices are under consideration by this group.

Learning Collaborative/Quality Improvement

From June 2011 through September 2012, the Alaska EHDI Program actively participated in the National Initiative for Children's Healthcare Quality (NICHQ) to strengthen collaboration with EHDI partners, as well as enhance parent support. A core team consisting of the EHDI Coordinator, a pediatric audiologist, an early interventionist and a parent participated in training and developing PDSA cycles. 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 program identified 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. Both facilities participated in the NICHQ process as extended partners and engaged in NICHQ activities. Responsibility for follow-up was delegated by each facility, resulting in a reduction in loss to follow-up/documentation for both facilities. One of the Aims of this Learning Collaborative was to improve the screening rate for out of hospital births; this aim was partly achieved through a strategy generated from the NICHQ experience.

NICHQ Extended Partner Meetings provided a forum for bringing together stakeholders around specific EHDI systems issues. For instance, there is interest in revising and spreading the audiology packet developed during the NICHQ to other audiology practices. Several of these partners have joined the EHDI Advisory Meeting. EHDI will continue to involve partners in the change process.

In preparation for this grant cycle, the EHDI Program re-convened the team of stakeholders who previously participated in the NICHQ Learning Collaborative, as well as inviting additional community members such as an audiologist from the native health system and a birth screening coordinator. The AAP Chapter Champion is also a member of the team. This team is dedicated to addressing areas of loss to follow-up by implementing quality improvement strategies through Plan-Do-Study-Act (PDSA) cycles and measure data driven quality improvement changes. The core Quality Improvement (QI) Team met and developed a monthly meeting schedule and identified aims for this grant cycle and strategies for PDSA cycles.

The EHDI Program will continue to focus quality improvement measures to reduce loss to follow-up. Sectors needing improvement will be driven by data analysis.

The following Aims will be addressed in this grant:

GOAL/AIM 1: Ensure all infants discharged from the hospital with a "refer" or missed screen will receive follow-up re-screening by one month of age.

GOAL/AIM 2: Ensure out of hospital births receive newborn hearing screening and appropriate follow-up in accordance with National EHDI 1-3-6 Goals.

GOAL/AIM 3: Ensure infants who do not pass their final hearing screening receive a diagnostic assessment by audiology no later than 3 months of age in accordance with National EHDI 1-3-6 Goals.

AIM/GOAL 4: Ensure infants/children diagnosed with a hearing loss receive seamless services from diagnosis through intervention and are offered family support.

AIM/GOAL 5: Establish a system of care connecting the EHDI Program with community partners who work with families of young children to ensure children are not lost to follow-up.

NEEDS ASSESSMENT

Two defining characteristics of the State of Alaska are the physical geography and the racial diversity of the population. Alaska is a large, sparsely populated state. The land mass of the state encompasses 571,951 square miles, averaging a population density of just 1.1 persons per square mile. This is the lowest population density of any state.

The 2012 Alaska population was estimated at 732,298, with 65% living in urban areas (Alaska Department of Labor and Workforce Development, 2013). Seventy percent were reported to be Caucasian alone, 16% Alaska Native/American Indian alone, 4% Black alone and 4% Hispanic. Twenty percent were reported to be Alaska Native/American Indian alone or in combination with another race category; this is an approximate proportion of the population eligible for native tribal health services.

Nine percent of the population lives in remote rural areas; of the people who dwell in rural areas, approximately 80% are Alaska Natives. Eighty percent of the population lives in urban areas defined as the census areas of Anchorage, Juneau, Fairbanks, Matanuska-Susitna, and Kenai Peninsula. These census areas generally correspond to the state's most populated communities of Anchorage, Juneau, Fairbanks, Palmer/Wasilla and Kenai/Soldotna. The Municipality of Anchorage is home to nearly half the state's population - 42%. Cultural diversity among the non-Native population is increasing. About half the students in the Anchorage School District are ethnic minorities and they speak 94 different languages.

Approximately 75% of Alaskan communities, including the state's capital city of Juneau, are not connected to the road system. Accessing "nearby health services" or specialized health care means travel by commercial jet, small plane, the state marine ferry system, all-terrain vehicles, small boats or snow machines. Some residents may travel distances equivalent to traveling from Washington, D.C. to New Orleans for even routine medical care. Moreover, severe weather can render travel impossible, creating especially critical situations in medical emergencies.

Health care delivery in Alaska consists of three separate systems. The Alaska Native Tribal Health Consortium (ANTHC) is a consortium of tribal entities that provides several levels of medical care: emergent/primary care at village clinics, primary and secondary care at regional hub hospitals, and tertiary care at the Alaska Native Medical Center in Anchorage. Funding for

the consortium is the product of several sources including federal IHS, Medicaid, private insurance and tribal consortium dollars.

The two other systems of care include private non-profit and for profit secondary and tertiary care hospitals and private health care providers including nurse practitioners, physician assistants and physicians as well as the extensive military system supporting the active duty and retired armed forces (army, air force and coast guard bases).

The geographic isolation of rural communities means significant challenges in assuring all populations have access to routine preventive care, acute medical and specialty care. Specialty care, even in urban areas of the state, is limited. For example, the only Level III/IV neonatal intensive care facility is located in Anchorage. Many communities have no facilities equipped for childbirth so pregnant women must leave their homes four weeks before their due date. Even well-child check-ups and prenatal exams are difficult to provide. Recruiting and retaining physicians, primary health care providers and allied health professionals, such as audiologists, for non-urban practices is also a barrier to providing health care services. A recent email to the Alaska EHDI Program inquiring if an infant born in Anchorage, but who resides in a remote region, was missed illustrates the challenges of follow-up for this population: *“The issue here as well is that the baby lives in Little Diomed and the only way to get from DIO [Little Diomed] to Nome is via helicopter and plane which is dependent on weather. The helicopter only flies out there twice a week. This child should not have been missed.”* In addition to logistics, the other major challenge for follow-up not addressed in this email is the associate cost of care in Alaska for very expensive air transportation and lodging.

Disparities

The largest differences in health trend status are between the native and non-native populations and between rural and urban populations. The majority of people living in rural areas are Alaska Native people. The health status of Alaska Native people is poorer than that of non-Native people in several domains. Living in remote communities with high unemployment rates, low income and barriers to accessing health care services are contributing factors.

Health care services are very difficult to deliver in rural Alaska due to high transportation costs and lack of skilled resources in the small communities. The Community Health Aide Program is a network of about 500 Community Health Aides/Practitioners (CHAPs) who work in village clinics to provide basic health care services and referrals. Often they are the only point of contact for medical issues and there is not have a physician or nurse practitioner in the community. CHAPs are inundated with acute care issues and do not have the time or resources for follow-up on issues such as NBHS.

Compared to the non-Native population, the Alaska Native population has poorer health outcomes in post-neonatal mortality; child, adolescent, teen (especially teen suicide), and female mortality; and childhood dental caries experience (among third graders), State Title V Block Grant Narrative – Alaska, 2014. A lack of running water and cramped housing contribute to a higher incidence of upper respiratory infections and associated ear infections and lung disease. The Alaska Native population experiences a disproportionate rate of loss to follow-up after a failed newborn screening and is a focus for quality improvement in this grant cycle.

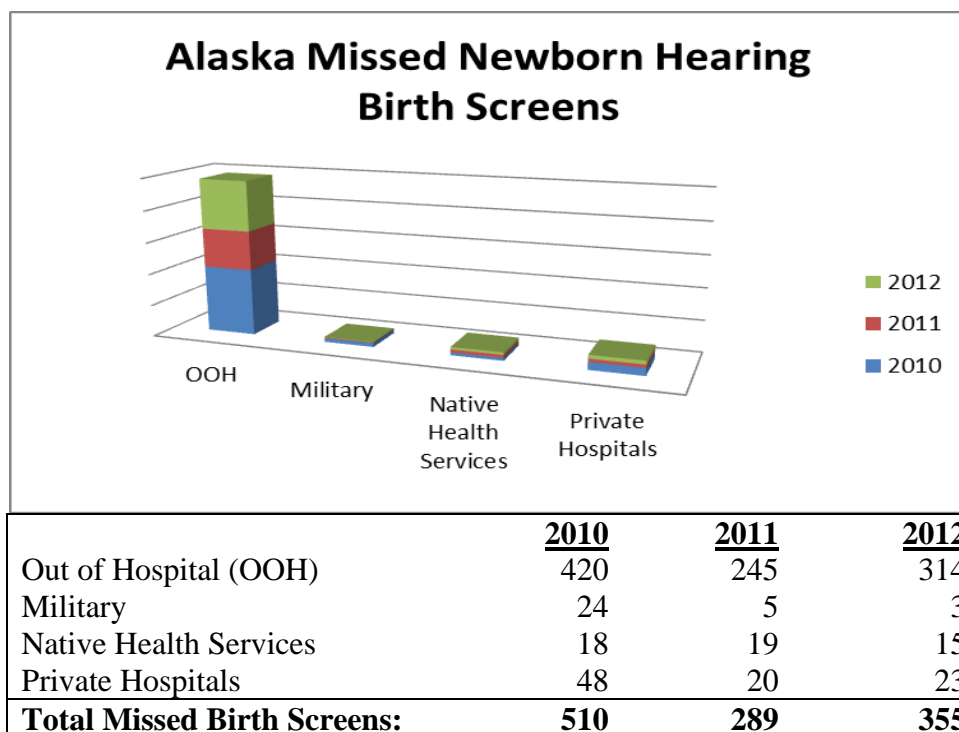
Alaska Data

Preliminary data for infants born in Alaska in 2012 indicates there were 11,117 live births. Racial breakdown for children born in 2012 is approximately 10% Asian, 4% Black, 25% Native Alaskan, 60% White, and 1% unknown (State of Alaska Bureau of Vital Statistics, 2013).

Data indicates the percentage of all Alaskan infants receiving hearing screens rose from 95% in 2009 to 97% in 2011 and 2012 (preliminary). The latter percentage, 97%, represents all infants born in Alaska. However, when calculating only infants born in hospitals, the percentage of newborn hearing screening for hospital births increased from 97% in 2009 to 99% in 2011 and 2012. 6% of all Alaskan babies are born out of the hospital; this rate, one of the highest in the nation for out of hospital births, accounts for the discrepancy between the total birth screened and the number of infants screened in hospitals.

The out of hospital birth population accounts for the highest percentage of missed newborn hearing screens. In 2009, only 38% of out of hospital births were documented to have been screened. Since that time, the EHDI Program has improved the screening rate for this population by placing screening equipment in four midwifery centers and three public health centers. Of note, the preponderance of out of hospital births does not occur in rural remote regions of the state; the latter population generally delivers at birthing hospitals which are part of the native health system. Aside from the midwifery center in Juneau, the state capital, the six other out of hospital screening sites are located on the road system in or near urban areas.

The screening rate for out of hospital births rose from 37% in 2009 to 60% in 2011 after hearing screening equipment was placed in communities with high out of hospital birth rates. Using data analyzed from the integrated AKEHDI database, the program began sending quarterly reports to midwifery centers listing the names of children associated with their midwifery practice and their screening status at the end of 2010 was 38%. In 2012, the screening rate for out of hospital births dropped to 52%; two factors may have influenced the decline in screening. The state stopped sending screening notification to parents by certified letter and the three public health centers that were providing hearing screening for this population started charging a nursing fee for administering the screening. To provide an alternative for this population, screeners were placed in the two additional midwifery centers, one in Anchorage and one in the Mat-Su Borough; screener equipment was already in place in Fairbanks and Juneau respectively. Preliminary data for out of hospital births for the first three quarters of 2013 indicate a screening rate of 70%. The EHDI Program will continue monitoring this rate and explore options for increasing screening in this population to 80%. While the screening rate for out of hospital births has increased, this population represents most of the missed screens in the state.



In the next grant cycle, the EHDI Program will continue to identify hospitals with missed screens and improve screening before hospital discharge by utilizing change strategies within the newborn nursery.

Lost Between Initial Screening and Rescreening						
YEAR	TOTAL	MILITARY	ANMC	Remote Regional Hospitals	PRIVATE	OTHER
2010	150	76 - (51%)	18 - (12%)	18 - (11%)	32 - (21%)	5 - (2%)
2011	72	12 - (17%)	12 - (17%)	18 - (25%)	27 - (38%)	3 - (4%)
2012	78	12 - (15%)	8 - (10%)	8 - (10%)	47 - (60%)	3 - (4%)

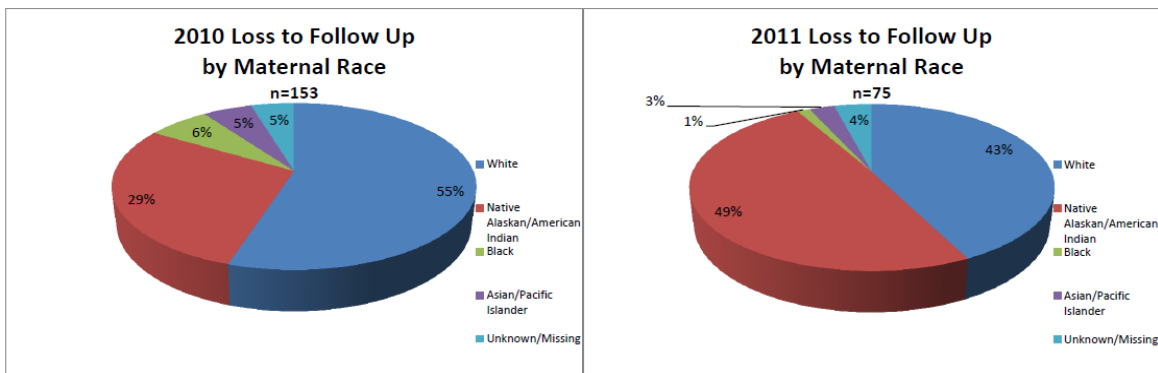
By 2010, the military birthing facilities accounted for more than half of the loss to follow-up/loss to documentation after failure to pass newborn hearing screening. The EHDI Program met with key personnel at Joint Base Elmendorf/Richardson (JBER) between October of 2010 and June of 2012 to address documentation and follow-up issues at JBER. The commander of the unit over audiology, with cooperation from pediatrics and the newborn nursery wrote a mandatory compliance manual for newborn hearing screening at the facility. All births for 2011 were reconciled and entered in the OZ database. Loss to follow-up/documentation for infants born at military facilities went from 66% in 2010 to 15% in 2011. To address ongoing turnover at military bases, the EHDI Program will engage these facilities in small steps of change that can be sustained through ongoing personnel changes.

Native health beneficiaries are another population with a high rate of loss to follow-up. Sixty percent of infants born at the Alaska Native Medical Center are discharged to remote regions of the state.(see chart below) Options for diagnostic evaluations in Anchorage, prior to returning to remote regions, for infants that do not pass their newborn screening are under discussion and there is a plan to develop a PDSA around this issue.

In 2011 and preliminary data for 2012, one particular hospital accounted for the majority of loss to follow-up among private hospitals in the state. A quality improvement plan is proposed to reduce loss to follow-up for this facility and other identified outliers.

EHDI will examine strategies from communication in the nursery through referrals to audiology.

The above data indicates most children lost to follow after screening did not return after hospital screening. The numbers of children that did not pass outpatient screening and did not follow-up with audiology are small. There were 21 in 2010; 9 in 2011 and 19 in 2012. In 2010, half of those children were from the native health system and half were from the military. As mentioned above, the military issue was remedied in 2011, accounting for the decline that year. Preliminary data for 2012 indicates 84% of the infants that did not follow-up with audiology in this group receive their health care in the native health system. This population is a strong focus of this grant.



Data for Confirmed Diagnosis of Permanent Hearing Loss after Refer on Screening:			
2008 = 16	2009 = 19	2010 = 20	2011 = 18

Alaska’s reported cases of hearing loss as a result of newborn hearing screening falls with the expected range. In 2011, Alaska’s prevalence rate was 1.6; consistent with the national prevalence rate of 1.5 as reported to the CDC. Of the 18 children diagnosed with hearing loss in 2011; 15 were diagnosed by 3 months of age which at 83% meets the mid-range performance rate as adopted by the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA).

Lost Between Audiologic Diagnosis and Entry into Early Intervention Program

In 2008, the EHDI Program signed a Memorandum of Agreement (MOA) with EI/ILP to receive named data on children with hearing loss who are receiving EI/ILP services. EI/ILP. The MOA (Attachment 6) required the 17 programs to obtain a signed release from parents to share data with the EHDI Program; this information is reported to the State EI/ILP office and then released to the EHDI Program. A PDSA quality improvement cycle was executed during the state's participation in the NICHQ 2011-2012; however the strategy did not result in change. This issue will be readdressed in this next grant cycle with the strategy of streamlining the process for obtaining a release. As a work around, the EHDI program released the names of infants born in 2011 with a diagnosed hearing loss to EI/ILP and the latter program reported the following information. Of the 18 cases of hearing loss, 15 were referred to EI/ILP; 11 were referred and eligible for services, ten children were enrolled in EI/ILP with eight of the ten enrolled before 6 months of age.

Audiology Capacity

The availability of audiologists specializing in pediatric audiology in Alaska mirrors the three separate systems for health care in Alaska: the military, Native Health Service and private. Audiology is available at the military bases located in Fairbanks and Anchorage. Both bases have the capacity to do a sedated diagnostic auditory brainstem response (ABR), however the priority for the department is provide care for enlisted personnel. This priority coupled with the challenges of support staff on military bases to conduct tracking and follow-up duties as well as frequent turnover among audiologists and their support staff and newborn nursery staff. The largest military facility located in Anchorage at Joint Base Elmendorf/Ft. Richardson is working with EHDI to operationalize policies that are sustainable through staff changes.

Central audiology services for the Tribal Health System are located in Anchorage at the Alaska Native Medical Center (ANMC), with audiologists located at a native regional hub medical facility in Nome; however they do not have the capacity to do sedated ABRs. Children from all regions are flown to Anchorage for diagnostics requiring sedation. In the private sector, children are generally referred to Anchorage for diagnostic assessment. While there are audiologists on the Kenai Peninsula, and in Juneau and Sitka that can screen children and do visual response audiometry, parents must drive long distances on the Kenai or fly to Anchorage from Juneau or Sitka, for a complete diagnostic work-up and hearing aid fittings. Fairbanks, with the addition of two new audiologists, now has the capacity to do sedated ABRs. While Medicaid does support air travel expenses for Medicaid eligible services, private insurance does not always cover any or all of the cost.

Improving loss to follow-up and early assessment will decrease the need for sedated ABRs. The EHDI Program has worked with ANMC to reduce the 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. In this next grant cycle ANMC will partner with EHDI to trial providing diagnostic ABRs in Anchorage before infants return to remote regions of the state.

Both the tribal health system and the private sector have ongoing recruitment for audiologists; however the profession remains a scarce commodity in Alaska. In 2012, there was a complete turnover of audiologists at both the military bases in the state. There is also a new group of

audiologists in the private facility in Fairbanks. Since the past grant cycle, the tribal health system lost audiologists at the regional hospitals in Bethel for the Yukon Kuskokwim Health Corporation (YKHC) and Dillingham (Bristol Bay Health Corporation; another audiologist, who lived in the YKHC region, now commutes from Idaho part of the year. All the above mentioned positions are currently vacant; as well as an audiology position in Barrow. Currently, audiologists are flown from ANMC in Anchorage to staff regional tribal hub audiology/ENT clinics. Families often must be flown to the regional clinics from more remote locations and weather and cost often impacts the “no show” rate at these clinics. When families do attend these clinics, children are often rescreened or are now older and may have middle ear effusions or infections. These regions account for a large portion of the state’s loss to follow-up and strategies for earlier diagnostics and intervention will be addressed in this next grant cycle.

Alaska Native Medical Center has the capacity to do cochlear implants; however in the private sector families must fly to Seattle for implants. Implant mapping is only administered in Anchorage. Aside from cochlear implants, digital hearing aids and ear molds are covered by Medicaid and the EHDI Program has a loaner hearing aid program for newly diagnosed children that are not Medicaid eligible and are not covered by private insurance or have tribal health benefits.

Facilities with high refer rates

The total refer rate for all birthing facilities 4%. Birth screening facilities that are identified with a higher rate of lost to follow-up also had a higher than average refer rate. 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. 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, designated staff conduct newborn hearing screenings also contributes to refer rates in the expected range. The EHDI Program also conducted site visits and training and a parent of a child with hearing loss, who is also a pediatric speech pathologist, has spoken to nursing staff on the importance of accurate screening and scripting the message to parents. The program also distributed the Newborn Hearing Screening Training Curriculum developed by NCHAM to Mother/Baby Unit Managers at all Alaska birthing facilities.

METHODOLOGY

Alaska’s EHDI Program has developed a strong statewide system and program infrastructure to support the Goals/Aims of this project. The program is advised by a committed group of stakeholders with the majority also participating in the EHDI Advisory Committee. Advisory committee members also participate on the Quality Improvement Team. EHDI also contracts with the Stone Soup Group to provide parent support to families of children who are Deaf/Hard of Hearing (Deaf/HOH).

OZ Systems, a web-based tracking surveillance system, has the capacity to provide the data necessary to identify components of loss to follow-up, (e.g. location, facility, mother’s age, etc.), as well as the data to measure quality improvement strategies. While the initial demographic

data is populated by newborn hearing screeners, the database is integrated with newborn metabolic screening. This integration provides the name of the infant's primary care provider (PCP), an essential element for decreasing loss to follow-up also providing a data match between the two screening programs. OZ Systems also provides technical support on database training and report extraction.

The EHDI Program is led by an experienced Program Manager whose advanced degree and experience is in the area of early intervention and children with special health care needs. In addition, the program benefits from a well-trained EHDI Health Program Associate (HPA). Both of the staff members are in their positions with the EHDI Program for over six years. The EHDI Program Manager was the team leader of the last NICHQ core team and the HPA was the data manager; they will continue in those roles for this grant cycle. The HPA will extract and review CDC data quarterly as another tracking measurement in Alaska's efforts to reduce loss to follow-up. The role of follow-up coordinator is shared between these two positions. The HPA sends the monthly fax-backs on all children with a "refer" or missed screen to birthing facilities, as well as produces letters to parents and PCP's. The EHDI Program Manager guides the follow-up process and has direct contact with parents, audiologists, PCPs, and early interventionists. This position is the lead for QI projects leading to system change.

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 actively promote the EHDI 1-3-6 National Goals in Alaska. A factor in selecting committee members was their capacity to represent statewide populations, e.g. representatives from the Alaska Native Health Consortium (ANTHC) are located in Anchorage, but travel to remote regions of the state, as do state representatives from Public Health Nursing and EI/ILP. Stone Soup Group is a parent advocacy organization with statewide contacts; parents representing different communication choices are represented on the committee. Audiology is representatives are from the private, tribal and military sectors and the AAP Chapter Champion is also an active member. Birth screeners, neonatologists, and otolaryngology are also part of the committee. In this forum, challenges and barriers to services are identified. Data from the EHDI program is shared and discussed. Issues identified in this forum have generated proposals for models for quality improvement.

In preparation for this grant cycle, the EHDI Advisory Committee met in September 2013 and prioritized the strategies proposed in this Funding Opportunity Announcement (FOA). The EHDI Advisory Committee prioritized the following strategies: 1) scripting the message to parents, 2) ascertaining the name of the infant's primary care provider, 3) making rescreening and/or audiology appointments before hospital discharge, 4) telephone reminders for appointments and 5) streamlining the referral process to EI and obtaining consent for release of information.

AKEHDI participated in the NICHQ Learning Collaborative from June 2011 through September 2012. The core team consisted of the EHDI Program Manager, a pediatric audiologist, an early interventionist, parent navigator, whose is the parent of child who is deaf, and data manager (Health Program Associate). This team reconvened in November 2013, committed to continue the quality improvement process; all but the early intervention representative, who will be a new member, received initial NICHQ training. Additional members to the core Quality Improvement

(QI) Team are a pediatric audiologist from Alaska Native Medical Center, birth screen coordinator from the tertiary birthing facility, and the AAP EHDI Chapter Champion. The team has agreed to meet a minimum of once a month, either in person or telephonically, to provide guidance and/or implement the improvement strategies and PDSA cycles. At the November meeting the QI team constructed some of the aim statements presented in this proposal. As the core QI team continues its work extended community partners will be invited to participate such as Title V and Early Head Start and other home visiting programs.

GOAL/AIM 1: Ensure all infants discharged from the hospital with a “refer” or missed screen will receive follow-up re-screening by one month of age.

Aim/Objective 1.1: By March 2017, 85% of all newborns who did not pass or who did not receive their newborn hearing screen will have a rescreen and/or audiology appointment by one month of age.

Aim/Objective 1.2: By March 2017, all birthing facilities in Alaska will have a refer rate of no more than 4%.

Demographic data and newborn hearing screening results, (missed, passed and refer), are entered into the OZ-System by all twenty birthing hospitals, four midwifery centers and three public health centers throughout Alaska. The state developed a process for sending fax-backs to all screening facilities on a monthly basis for all infants with an “in process” record. The facility responds back to the EHDI Program with an update on the child’s status; i.e. infant has appointment for rescreen, unable to contact, rescreen was completed, or data was not entered. The information collected from this report is used to send letters to parents on the need for follow-up and notification to the child’s PCP. In 2012, an enhancement of “hearing reminders” was added to the database. These reminders provide prompts on stages of follow-up notification should to parents, PCP’s and audiologists. The EHDI Program will be reviewing the timeline for hearing reminders with the goal of formalizing guidelines for earlier notification to parents and providers. The guidelines will be presented to the EHDI Advisory Committee and a PDSA will be developed to track if the strategy of incremental notification correlates with a decrease in loss to follow-up.

Consistent and accurate data entry is essential for successful tracking and surveillance. High staff turnover at birthing facilities throughout the state requires ongoing training from the EHDI Program for hearing screeners and mother/baby managers. Database training is available through webinars from OZ Systems, in person training by EHDI staff when travel is possible and telephonically as an alternative. To sustain training activities, OZ recording trainings that the State can use for future trainings and the State is developing the capacity for “Go to Meetings” for distance delivery trainings.

In this next grant cycle, the EHDI Program will develop an online survey to ascertain how birth screeners are doing the following: 1) scripting the message to parents; 2) identifying a second point of contact for families; 3) making rescreening and or audiology appointments for the infant before hospital discharge; and 4) how parents are given reminders of appointments. After analyzing the results of the survey, the EHDI Program Manager will contact facilities that need

technical assistance in implementing the above strategies Results of this survey will also guide future PDSAs and small steps of change.

The EHDI Advisory Committee and the QI Team strongly support the strategy of “scripting the screener’s message to parents”. The State developed a “*do and don’t say*” placard and it was trialed with a few birthing centers. In this funding cycle, the state will survey which facilities are using the scripted message and receive feedback on its utilization. A new PDSA will be trialed with a facility with a high rate of loss to follow-up and results will be tracked and the plan modified through change cycles. The goal is to spread the scripted message to birth screeners statewide.

The EHDI Program sends Practice Profiles to all birth screening facilities quarterly. This aggregate report not only provides data on screening status and numbers of outstanding records, but it also reports on the refer rate for each facility. The EHDI Program Manager notes concerns, as well as successes, on the report which is sent to the head of the mother/baby unit or hearing screening coordinator. Facilities with high refer rates will be contacted and plans for corrective action discussed as well as opportunities for quality improvement plans using the PDSA model. This process was successful in significantly reducing the refer rate (which may represent false positives) for infants discharged to rural/remote regions of the state from the largest tribal health facility.

GOAL/AIM 2: Ensure out of hospital births receive newborn hearing screening and appropriate follow-up in accordance with National EHDI 1-3-6 Goals.

Aim/Objective 2.1: By March 2017, the screening rate for out of hospital births (i.e. home births, midwifery centers, etc.) will increase from 70% to 80%.

Aim/Objective 2.2: By March 2017, 90% of out of hospital births will be screened by thirty days.

In Alaska six percent of infants are born out of hospital either at home or at midwifery centers (free standing birthing centers). From 2011 to the present, the EHDI Program has used HRSA funds to purchase and loan screening equipment to four midwifery centers located in Anchorage, Fairbanks, Juneau and Wasilla. A Memorandum of Agreement was signed with each of the four midwifery centers (Attachment 4) and hearing screeners report their complete birth census into the OZ, following the same data flow chart as birthing hospitals (Attachment 4). Screeners were additionally placed in three public health centers in communities with a high rate of out of hospital births. In 2009, the statewide screening rate for out of hospital birth was 38%. As of the first three quarters of 2013, the screening rate for this population was 70%. After equipment was placed in the four midwifery centers, the screening rate for those centers went from an average of 33% to an average of 95%.

As part of the EHDI statute, the program receives a monthly list from the Bureau of Vital (BVS) of all birth certificates issued to infants born out of hospital. The EHDI Program checks this list against the OZ database and creates records for infants not in the database. Letters are sent to parents of infants that are not identified in OZ as having a screening result. From database

records, quarterly reports, similar to the hospital practice profiles are sent to all midwiferies. All midwives with records in the database are also sent a named report of infants listed in their practice along with their screening status. This informs midwives in practices that do not have screening equipment of the screening status of their clients. The EHDI Program will also contact midwives on an annual basis to solicit input on improving screening and follow-up for this population.

In this next grant cycle, the EHDI Program will contact a parent of a child born out of hospital with a hearing loss identified through newborn hearing screening to better outreach to parents who might be hesitant to screening. The program will pilot a parent letter, along with the state letter, as a strategy to improve the screening rate. The program will also extract data from OZ to determine if there is a difference in screening rates between infants born at home and those born at midwifery centers and then target education accordingly.

Aside from improving the screening rate, the EHDI program will explore strategies for earlier screening, by thirty days, in this population. In the last learning collaborative, the EHDI Program implemented a PDSA to improve earlier notification to parents. The infants on the list of OOH births received from BVS may be more than 30 days of age. EHDI will continue the quality improvement process of utilizing demographic data from newborn metabolic screening for more timely notification to parents. (This excludes the four midwifery centers with screening equipment that generally offer screening at the one week check-up if not sooner and enter their data directly into OZ.)

GOAL/AIM 3: Ensure infants who do not pass their final hearing screening receive a diagnostic assessment by audiology no later than 3 months of age in accordance with National EHDI 1-3-6 Goals.

Aim/Objective 3.1: By March 2017, the rate of loss to follow-up between last hearing screen and diagnostic evaluation will be reduced by 50% for private hospitals/birthing centers in Alaska.

Aim/Objective 3.2: By March 2017, the rate of loss to follow-up between last hearing screen and diagnostic evaluation will be reduced by 50% for children receiving their health care in the native health system.

Aim/Objective 3.3: By March 2017, the rate of loss to follow-up between last hearing screen and diagnostic evaluation will be reduced by 50% for children receiving their health care in the military health system.

As previously stated, health care delivery in Alaska consists of three separate systems. The Alaska Native Tribal Health Consortium (ANTHC) is a consortium of tribal entities that provides several levels of medical care: primary care at village clinics, primary and mid-level primary care at regional hospitals, and tertiary care at the Alaska Native Medical Center in Anchorage. (2) Military hospitals and the Veteran's Administration serve the military population. (3) Private sector physicians, health care providers and hospitals that can serve any individual in the general population. The unique characteristics of these systems are addressed

in three separate objectives related to scheduling diagnostic evaluations by three months of age. The uniqueness of these three systems and their populations require different interventions. The EHDI program, along with the EHDI Advisory Committee and QI team will look at revising the data flow chart (protocol) for each of the three systems.

The EHDI protocol outlines out-patient rescreening at all private hospitals for infants that are missed or do not pass their in-patient hearing screening. Data from OZ identifies certain facilities with a high rate of loss to follow-up after initial or rescreening. A comparison of these hospitals with those having a low rate of loss to follow-up indicates that those hospitals with a high rate are not scheduling audiology appointments after a failed rescreen. The EHDI Program will be contacting those facilities and discussing barriers to scheduling appointments. Support for a quality improvement project to schedule audiology appointments after a failed screen will be offered to those facilities. This will be a multi-prong approach. The hospital will arrange for audiology follow-up and the PCP will be notified of the failed screen by the birth screener. The AAP Chapter Champion will provide education to promote increased awareness of the need for audiology follow-up among PCP's. In addition to the hospital, the EHDI Program will send fax notification to PCP's of a failed screen if an audiology appointment is not documented in the database. The program will develop a PDSA to track the outcome of faxes sent to PCP's to determine if the fax notification results in a prompt response by the PCP, leading to an early diagnostic appointment. At one particular hospital with a higher than average rate of loss to follow-up for rescreens and diagnostic appointments, the QI team recommended a PDSA with the hospital, public health center and EHDI to improve the loss to follow-up rate for this particular community.

ANTHC has unique strengths and challenges that differ from the private sector. If an infant lives in the Anchorage area, the protocol for private hospitals is applicable. In fact those residing in Anchorage have access to a team of audiologists at ANMC, which is a strength of this system. However, 60% of the infants born at ANMC return to rural/remote communities that may not be on the road system and do not have audiologists in their community. The population of infants that do not pass their final screening are placed on a list to be seen at an itinerant/regional hub audiology clinic, where they are historically then rescreened. It may be months, and sometimes longer, before they are flown to Anchorage for a diagnostic evaluation. A member of ANMC's audiology department is on the core QI team and is committed to working with the EHDI Program to change this process. A strategy is proposed to schedule and administer a diagnostic audiology assessment in Anchorage for infants that do not pass their final screen prior to being discharged home. This strategy will be developed into a PDSA for testing, analysis and adoption/adaptation.

Some infants are born at tribal regional hospitals located in rural/remote parts of the state. Only two of those facilities have an audiologist on staff; the capacity for a non-sedated pediatric diagnostic evaluation is available at only one of the two locations. The audiology department at ANMC travels to five of seven tribal regional hospitals. Hampered by weather, scheduling issues and cancelled appointments, (parents often need to fly to the regional hospital), there may be delays of months for rescreening and longer for a diagnostic work up in Anchorage. A quality improvement cycle focused on reducing the delay will be another focus of quality improvement efforts. Strategies for diagnostic evaluations by three months of age will be developed into a

PDSA for testing and examination. The team will also be examining opportunities for tele-audiology. This will require significant support from ANTHC, regional hospitals and rural communities.

The third population that is lost to follow-up after a failed screen receives their medical care through the military. Both the military bases have audiologists; however there is frequent turnover in audiology staff every few years. This group deviates from the state protocol in that after the hospital screen, infants are generally rescreened in the respective audiology department. The EHDI Program will partner with military personnel to develop strategies that will lead to modifications of the mandatory compliance manual for newborn hearing screening which was written at the largest military base in Alaska and explore the possibility for adoption at the other military facility in the state.

AIM/GOAL 4: Ensure infants/children diagnosed with a hearing loss receive seamless services from diagnosis through intervention and are offered family support.

Aim/Objective 4.1 By March 31, 2017 the EHDI Program will increase the number of children enrolled in EI/ILP Part C by 6 months of age from 44% to 75%.

Aim/Objective 4.2: By March 2017 100% of all parents of children diagnosed with a hearing loss will be offered family support through Stone Soup Group parent navigation services.

A critical element to identifying infants/children lost to follow-up is to improve collaboration and the tracking of children from diagnosis to early intervention (EI) services. EI/ILP resides in a different division than the EHDI Program; however, both programs are located within the Department of Health and Social Services. Intervention services are provided by 17 non-profit grantees, located throughout the State of Alaska. A Memorandum of Agreement (MOA) was signed between EI/ILP and EHDI in 2008 for a name exchange of information between the two programs (Attachment 4). At this time, releases must be obtained by the 17 grantees directly from parents. A PDSA for obtaining releases directly from the grantees was trialed during the NICHQ Learning Collaborative; however it did not lead to an improvement in the number or releases received. Streamlining the release process between the two programs will be revisited in this grant cycle.

This past year there was significant turnover of audiologists throughout the state. In addition, there was significant change in early intervention staff, including the resignation of the EI/ILP, Part C Coordinator and the state EI/IP program specialist assigned to EHDI. As a result, education is planned for both groups to improve understanding of both programs. Once the new Part C Coordinator is on staff, the MOA between the two programs will be reviewed and modified accordingly. Strategies for streamlining the process for obtaining releases of information will be explored and PDSAs will be developed to test the strategies. The goal is to develop a protocol for referrals to EI/ILP with a feedback loop on enrollment back to the EHDI Program.

The EHDI Program added an EI/ILP module to the EHDI database where audiologists can download EI/ILP information and a referral form directly from the database. The module has a

link to the EI/ILP website which identifies the EI/ILP grantee for specific communities. A referral recorded on the database will trigger an email notification to the EHDI Program and the state EI/ILP office that a referral to an EI/ILP program was made. Audiologists were trained on using this section of the database through web-based training; training for new audiologists is provided as needed. The module can also track the status of a referral through enrollment and Part C determination.

Access to the EI/ILP module is available to the 17 grantees and electronic referrals to individual EI/ILPs can be sent directly to the EI/ILP program in which the child will be enrolled. However, it was requested by EI/ILP that referrals be sent only to the state office. The state's largest EI/ILP program is located in Anchorage and has membership on the EHDI Advisory Committee. This program generally has half of the children diagnosed Deaf/HOH. PDSA's to improve communication and timely enrollment will be advanced with the goal of developing an effective process between the two systems.

A parent navigator from Stone Soup Group (SSG) assigned to the EHDI Program provides support, assistance with navigating the system of services, and information to families diagnosed with hearing loss. The role of parent navigation will also be promoted throughout EI/ILP as a mechanism for enhancing care coordination and assisting families with the transition to intervention and reducing loss to follow-up. Education on parent navigation to community providers will be offered. The parent navigator is looking at options for joining with a national organization such as Hands and Voices. Opportunities for supporting parents from different geographical regions and different cultures will be explored in this next grant cycle. Feedback from parents on mechanisms for support will also be examined as means to connect parents and reduce loss to follow-up.

AIM/GOAL 5: Establish a system of care connecting the EHDI Program with community partners who work with families of young children to ensure children are not lost to follow-up.

Aim/Objective 5.1: By June 2015, the EHDI Program will re-establish a core team with a focus on quality improvement strategies to decrease loss to follow-up

Aim/Objective 5.2: By June 2015, the EHDI Program will increase the knowledge of newborn hearing screening to programs working with young children.

Aim/Objective 5.3: By March 2015, the EHDI Program will collaborate with community partners on strategies to decrease loss to follow-up.

The EHDI Program reconvened the core team from the previous NICHQ project, consisting of the EHDI Program Manager as the team coordinator, a pediatric audiologist, a parent navigator and data manager (health program associate). A new early interventionist will be added to the QI team and the team is enhanced by an audiologist from ANMC, a birth screening coordinator and the AAP Chapter Champion. In preparation for this next round of funding, the QI team and the EHDI Advisory Committee reviewed the strategies identified by the learning collaborative for reducing loss to follow-up and both groups chose the following: 1) scripting the screener's message to parents, 2) using fax-back forms between multiple providers, 3) making rescreening

and or audiology appointments for the infant at hospital discharge, 6) telephone reminders for appointments, 7) streamlining the EI referral process and obtaining a consent for release of information. The team felt the state has a robust data tracking system through OZ and the name of the PCP can be accessed through newborn metabolic data in the OZ database. The issue of making two audiology appointments will be further discussed at the EHDI Advisory Meeting. As part of the last NICHQ Learning Collaborative, the pediatric audiologist on the core team trialed an audiology packet at her practice. Strategies in the packet included the audiologist calling parents the night before the appointment, which reduced the rate of no shows. It also standardized a process for intake and diagnostics and data entry. This packet will be revised and tested with other audiology practices through a PDSA process. After analysis and any required revisions it will be spread to audiologists throughout the state.

The EHDI program has built a relationship with the Early Head Start and Parents as Teachers programs and will seek opportunities for providing education to those groups at meetings and/or conferences. The program supplied OAEs to both programs and will look at options for future collaboration to capture children that might otherwise be lost to follow-up. We will also partner with these programs on opportunities for culturally competent outreach. The program will also outreach to the Home Visiting Programs to provide education and explore opportunities for partnership. The “Sounds and Silence” video will be redistributed to community health aides in the native health system. All of these contacts provide a safety-net for families that may be lost to follow-up.

The EHDI Program will also meet with the immunization program to discuss mechanisms for reaching “hesitant” population. Collaboration with this program may be a source of updated information on families lost to follow-up with EHDI. EHDI had preliminary meetings with the Alaska Immunization Program and will continue to explore opportunities for accessing their VacTrAK database in the next grant cycle.

The Anchorage School District, which also has administrative and outreach responsibility for the Alaska School for the Deaf statewide, has representation on the EHDI Advisory Committee and is exploring options for a transition program for children who are deaf/HOH into school district preschool services beginning at two and a half years of age. As there are 94 languages spoken in the Anchorage School District, the EHDI Program will collaborate with the school district and EI/ILP that serve this region to discuss working with families of different cultures where English is the secondary language. Strategies for working respectfully and accessing services for different cultures will be addressed.

In January 2013, a doctoral student from the community psychology program presented to the EHDI Advisory Committee on interaction with Hmong families in Alaska. This presentation received positive feedback and requests were made by the advisory committee to consider presentations on other cultural groups in the future.

To reach 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 Spanish, Hmong, Tagalog, Russian, and Korean. The brochures are widely distributed throughout the state at birthing hospitals, primary care centers, public health centers and midwifery centers. The

Communicate with Your Child Brochure developed by NCHAM was printed with Alaska specific information and is available for distribution.

Sustainability

Alaska's EHDI Program is an unfunded mandate. Without HRSA funding the state would need to divert funds from other public health projects and consider revenues from clinics and newborn metabolic screening to support the program.

The Division of Public Health and Title V programs are committed to institutionalizing Continuous Quality Improvement on an organizational level. This commitment from division and Title V leadership will ensure the sustainability of quality improvement efforts on the organizational and programmatic levels. However, there is still a need for technical assistance and a quality assurance role from the state program staff to oversee EHDI, and provide data and to guide program activities.

All birthing facilities in the state are screening infants and the screening rate for hospitals is 99%. All facilities with screening equipment and audiologists administering diagnostic evaluations report into the database. Funding from the Center for Disease Control and Prevention (CDC) supports the database contract with OZ and a percentage of the Health Program Manager position. The aims of this grant are designed to develop strategies to decrease missed screens, particularly in the out of hospital birth population, and to reduce lost to follow-up at all stages of the early hearing detection and intervention system. Through small tests of change, leading to bigger tests and eventual system spread, it is believed that systems developed through this process will be formalized and sustainable. Products and practices developed during this project, such as training modules and making appointments for families before hospital discharge, will promote ongoing best practice. These strategies will support families of children with hearing loss and assist providers in providing timely standard of care.

WORK PLAN (in separate document) – Attachment 1

RESOLUTION OF CHALLENGES

The Alaska EHDI program has a dedicated team of community stakeholders committed to the quality improvement process. This is a strong foundation for implementing activities proposed in the work plan. A potential challenge to implementation is commitment to the PDSAs and proposed strategies on the part of members of the organizations represented by the QI team. Improvement results demonstrated by data and alignment with the goals of community organizations will improve success of the project.

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. There is also a statewide shortage of health care professionals, including audiologists. A community health aide/practitioner is often the primary care provider for the infant and family. It is a challenge to provide follow-up medical care, including

audiology diagnostics, 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. If infants are discharged home after a failed screen, the above obstacles impact follow-up. In addition, children are frequently placed on a list to be seen at itinerant clinics where they are rescreened and diagnostic assessment is delayed.

Possible Resolution: Coordination with the Alaska Native Medical Center (ANMC) in Alaska, the tertiary referral center for tribal health, is essential for problem solving issues surrounding access to follow-up. The pediatric audiologist and otolaryngologist are active participants on the EHDI Advisory Committee and essential partners for small tests of change leading to quality improvement. A proposed strategy for infants who do not pass screening is to scheduling audiology diagnostics in Anchorage prior to families discharged home. A long range solution is to explore options for tele-audiology for infants in remote locations. This will require commitment on the part of tribal health

Challenge #2: Overcoming the HIPAA/FERPA issues regarding data sharing with Early Intervention are essential for measuring the state's success in meeting the National EHDI 1-3-6 Goals. 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). The seventeen grantees that implement early intervention programs throughout the State are responsible for obtaining releases from families to report children with hearing loss to the EHDI program. This is an ongoing issue that needs to be resolved as to date very few releases have been obtained and few names released for matching purposes.

Possible Resolution: A Memorandum of Agreement (MOA) with the Early Intervention Program was written and signed by the two division directors in 2008. There is new leadership at EI/ILP and the MOA will be reviewed. EI/ILP is also interested in the quality improvement process and this is an opportunity for partnering to implement change strategies. The EI/ILP module in the EHDI database is a mechanism for audiologists to make referrals directly to the appropriate EI/ILP. This module assists EHDI in tracking referrals and provides information to EI/ILP and is a vehicle for a two-way exchange of information.

Challenge #3: Staff shortages and staff turnover are an ongoing challenge in the State. They occur at all levels and impact all components of the EHDI process including: birth screeners, audiologists, early interventionists, speech pathologists, physicians. Communication venues are essential to ameliorate the impact of ongoing turnover.

Possible Resolution: Staff turnover can affect the quality of data entry, screening standards and follow-up. Consistency in data entry and timely reporting are necessary in order for the EHDI Program Manager and EHDI Health Program Associate to follow-up on missed and failed screens. Ongoing training through webinars, self-study modules as well as telephonically and through site visits are mechanisms for training staff. Standardizing a scripted message for birth screeners and audiologists will support consistency in care through staff changes. Disseminating *Just in Time* materials to PCPs will also assist in standardizing care.

Challenge #4: Geography and access in remote regions of rural Alaska pose significant challenges to timely follow-up. Children born at remote regional hospitals do not have access to

audiology in their community or region and need to be flown to Anchorage for diagnostic follow-up.

Possible Resolution: Solutions supported by this grant will focus on improving timely notification to parents, PCPs and audiologists. Strategies to streamline the process for diagnostic audiology appointments will be explored with tribal health through participation in the quality improvement process. The feasibility of tele-audiology will be discussed.

EVALUATION AND TECHNICAL SUPPORT

Evaluation of progress on meeting the aims/goals/objectives for this grant will be based on improvement in reaching the National EHDI 1-3-6 Goals. Evaluation will be ongoing utilizing the process and outcome measures identified in the work plan to determine success in reduction in the rate of loss to follow-up with the goal of 20% reduction by 2017.

The EHDI database hosted by OZ Systems collects named, unduplicated, identifiable, accurate data on all occurrent births. Through monthly and quarterly data reports, the state has the capacity to analyze success in reaching the Aims outlined in this project. The CDC annual data survey is another mechanism for determining the state's success in reduction in the rate of loss to follow-up. The state adopted the practice of analyzing quarterly CDC data recommended by the NICHQ Learning Collaborative. Demographic data will identify trends and guide program development and emphasis. For example, the EHDI Program will analyze missed screens in the out of hospital birth population to determine if misses are more prevalent in home births compared to those at midwifery centers. This information will lead to focused strategies and small steps of change that have a greater likelihood of success. Both the EHDI Program Manager and the HPA very experienced users of the database and skilled in running reports and extracting data.

Data will be shared with the QI Team and the Advisory Committee and will be utilized to identify and modify PDSA strategies. Input and information from stakeholders will also enrich evaluation efforts, e.g. a data match with early intervention. A logic model was drafted to guide program evaluation and will be reviewed and finalized with input from the QI team and EHDI Advisory Committee. The logic model will illustrate a shared vision of the activities and expected outcomes of the project.

The EHDI Program resides in the Section of Women's Children's and Family Health in the Division of Public Health (the State's MCH Title V and Children and Youth with Special Health Care Needs Agency). (Attachments) The Perinatal and Early Childhood Health Unit is managed by a Perinatal Nurse Consultant who co-manages the Newborn Metabolic Screening Program which enhances the collaboration between newborn screening programs. The integrated database shared by the two programs provides essential data to assist in reducing loss to follow-up. This position also manages the Alaska Maternal, Infant and Early Childhood home visiting and Healthy Start programs and provides a vital link between those programs. The MCH Indicators Program Manager located in the MCH Epidemiology Unit assists with data analysis and relevant data on state and national trends.

The EHDI Program Manager was the coordinator of Alaska's team at the 2011-12 NICHQ project and will continue to lead the Quality Improvement Team. She has experience in building successful coalitions to address the needs of children with special health care needs. She also 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 Health Program Associate is responsible for overall database management of the OZ Systems database used by the EHDI Program. The HPA was the data manager in Alaska's NICHQ project and will continue in that role for this grant cycle. This position runs data reports, assesses quality of data entry and implements quality assurance procedures for accurate data entry. The position is responsible for producing monthly reports for the fax back system and sends letters to parents and faxes to PCPs. The above positions form a cohesive team. They share the function of follow-up coordinator to work towards the aims outlined in this application.

Technical support from OZ Systems and their program coordinator is an asset to achieving data integrity. The OZ Program Coordinator provides technical assistance to running reports that extract data for program analysis and problem solves data entry difficulties with users. This position also conducts database webinars and provides manuals for data use and has worked with the EHDI Program Manager to record trainings for new users.

The EHDI Advisory Committee worked with the EHDI Program Manager 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 program's brochure was adapted for out of hospital births. The advisory committee has representation from the Alaska Native Tribal Health Consortium and collaborates with this group to develop strategies and activities that are relevant to that population.

ORGANIZATIONAL INFORMATION

The EHDI Program is in the Perinatal and Early Childhood Health Unit within the Section of Women's, Children's, and Family Health whose mission is to promote optimum health outcomes for all Alaskans. This section is in the Division of Public Health which resides in the Department of Health and Social Services in the State of Alaska. The mission for the Department and the Division is "To promote and protect the health and well-being of Alaskans".

At this time the Division of Public Health is working to put in place the pieces for a gold-standard public health organization, and to that end has conducted a statewide health assessment and is in the process of completing a statewide health improvement plan. In addition, the agency has conducted a self-assessment and has a strategic plan. The division is working to build a cohesive performance management system and a culture of quality improvement. Although there are no specific plans for accreditation at this time, the organization is striving to excel as an organization and in that pursuit, to meet the standards of the Public Health Accreditation Board.

The EHDI program is managed by a Public Health Specialist (PHS) II, who is the EHDI Program Manager, with support from a Health Program Associate (HPA) and an Office Assistant II. The HPA is responsible for overall database management and assists the PHS II in data analysis. The two positions share the functions of follow-up coordinator. Follow-up is guided by the EHDI Program Manager and the HPA runs reports and exports follow-up letters and faxes from the database. The EHDI Program Manager is the Quality Improvement Team lead and facilitates the EHDI Advisory meetings. Both positions were involved in the NICHQ Learning Collaborative 2011-2012 and will apply PDSA strategies learned to reduce loss to follow-up in this grant cycle.

The Perinatal and Early Childhood Unit is managed by a Perinatal Nurse Consultant. This position also oversees the Newborn Metabolic Screening (NBMS) Program, the State-sponsored Genetics Clinics and the Nurse Home Visiting Program. She collaborates with the EHDI Program Manager on database integration and mutual screening goals as well as integration of programs for children with special health care needs.

Another unit within the Section of Women's, Children's, and Family Health is the Maternal Child Health (MCH) Epidemiology Unit which collects and manage data for several large surveillance systems including the Pregnancy Risk Assessment Measurement Survey (PRAMS) and the Childhood Understanding Behaviors Survey (CUBS), a three year follow up study to PRAMS. Recent publications include the "2012 Alaska MCH Data Book", the "2011 Alaska Native Edition" and the "2008 Health Status Edition". The MCH Epidemiology Health Program Manager III is the Title V MCH Epidemiologist. This position will track and analyze data for this grant and assist on reporting on performance measures.

Legislation mandating newborn hearing screening was passed in May 2006 and was enacted on January 1, 2008. Regulations were written and implemented at that time. There are provisions in the mandate and the regulations around screening, reporting, and connections to audiology and early intervention. Newborn hearing screeners and audiologists report to the State by entering data directly into the OZ database. The State worked with the database contractor (OZ Systems) on an integrated child health profile that integrated newborn hearing screening and newborn metabolic screening; this was accomplished in 2008. In the past year the system was modified to transmit HL7 messages from the Oregon Health Sciences laboratory, which is the contractor for NBMS, to the OZ database. This integration provides a match between the two screening programs, updated demographic information and the name of the child's PCP at the time of the second screen. NBMS data is downloaded into the database on a daily basis and indicates which facilities are behind schedule in entering hearing screening data as well as data on out of hospital births. Additional applications will be explored in the future, such as integration with the Alaska Birth Defects Registry.

Data from the EHDI database, along with data from MCH Epidemiology Unit, is used to determine target populations for education and change strategies. For instance, information on out of hospital birth populations will be used to determine if there are common characteristics among parents that refuse screenings. As previously mentioned the general newborn hearing screening brochure was modified for out of hospital births and was reviewed by a group of parents as well as the state's Public Information Team for culturally and linguistically competent

and health literacy. The presentation on beliefs of the Hmong population in Alaska was well received by the EHDI Advisory Committee as infants from this population have been identified with hearing loss and follow-up is an issue. The advisory committee requested presentations on other cultures. The EHDI Program continues to work with Alaska Native Health Consortium on strategies that will result in timely follow-up for this population.

Over 10% of Alaska's births are born on the two military facilities, one in Fairbanks and the other in Anchorage. The EHDI Program has outreached and established relationships with both facilities to meet the unique needs of military parents and the continual rotation of staffs. The EHDI Program Manager meets with the each military facility yearly and they receive monthly fax-back reports. EHDI identifies a key contact at each facility and pays attention to the rotation schedule for smooth transitions.