

**Project Narrative  
Alaska Early Hearing Detection and Intervention  
2020-2024**

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## **INTRODUCTION**

The State of Alaska is requesting funding to support Alaska's Early Hearing Detection and Intervention (EHDI) Program to ensure comprehensive and coordinated systems of care so that families with newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing (DHH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI) services.

Continuation of federal funding in support of Alaska EHDI will ensure that early identification through screening, and connection with diagnostic and treatment services, including early intervention and family support, are part of a comprehensive system of care for all Alaskan children with hearing loss.

### **Background**

Alaska has built the infrastructure and a state-wide system to support the National 1-3-6 goals. This includes screening at birth or by one month of age, audiological assessment for infants that do not pass screening by three months of age, and referral to and enrollment in EI by six months of age for those children with diagnosed hearing loss. The EHDI Program is located within the Section of Women's, Children's, and Family Health (WCFH) which is located in the Division of Public Health, Department of Health & Social Service. When Alaska first received federal funding to implement the EHDI Program in 2000, the hearing screening rate for infants discharged from the hospital was 60%. In 2018, the hospital birth screening rate grew to 99%. The screening rate for all births (excluding infants who died or there was parent refusal) in 2017 was 96.5%, with the majority of those who missed a screening being out of hospital (OOH) births. The HRSA federal funding has helped enable Alaska to demonstrate this improvement.

The EHDI Program continues to support birth screening, but has been shifting the focus of the program to reducing the number of children lost to follow-up after screening, and ensuring earlier access to diagnostic audiology and EI services. There has been success in meeting the HRSA objective of decreasing loss to follow-up. In 2014, the state reported a loss to follow-up/loss to documentation rate of 42.6%. By 2017, this rate had decreased to 28.1%. Building on these past successes, the next project period will focus on supporting and optimizing statewide programs and systems of care to ensure that newborns who refer on newborn screening receive diagnosis and EI in a timely manner. This can be accomplished through timely newborn and infant hearing screening, evaluation, and diagnosis and implementing as early as possible, appropriate interventions to optimize language, literacy, and social-emotional development.

### **Legislation**

Through the efforts of EHDI stakeholders, including families, health care providers, and audiologists, the legislation mandating newborn hearing screening in Alaska was passed into law in May 2006. The statute and accompanying regulations took effect in January 2008. The law

follows the National EHDI 1-3-6 goals for screening, diagnosis, and intervention but also mandates insurance coverage for hearing screening. The mandate includes a screening within 30 days of birth and confirmatory hearing diagnostic evaluation for newborns who do not pass, and referral to an EI provider. It requires birthing hospitals and audiologists to report screening and assessment results into the State's EHDI web-based database. It also requires the Section of Health Analytics and Vital Records (HAVRS), formerly known as Bureau of Vital Statistics (BVS), to provide EHDI with a list of OOH births and for the EHDI Program to notify these parents of the necessity of newborn hearing screening.

## **Family Engagement and Education**

The EHDI Program has a very strong commitment to, and success, with engaging parents, families and self advocates. Following national guidelines for parent engagement, the Program received Department approval to offer parent honorariums in 2017. Alaska's Family 2 Family Health and Information grantee, Stone Soup Group (SSG), administers the family honorariums for the program. This tangible recognition of the value of parent involvement has positively affected parent engagement, and increased participation by Family Leaders during the 2017-2019 time period. Alaska has had long standing programs and supports for families who choose American Sign Language. To increase choice and diversity, EHDI Family Leaders started an Alaska Chapter of AG Bell in 2017 in response to parent requests for supports and resources for families who choose listening and spoken language communication. Families of DHH children are now forming an Alaska Chapter of Hands and Voices to provide support for families regardless of their communication choices. The EHDI Program collaborates and engages with all of these entities to ensure we are inclusive of all parent options.

The EHDI Program is committed to encouraging and supporting family leadership and continues to work to meet the needs identified by Alaskan families. The EHDI Parent Work Group meets three times a year to review Quality Improvement (QI) projects and advise the program from a parent perspective. It is open to new members and those do not have the capacity or interest to participate in the broader EHDI Advisory Committee. In 2019, this Parent Work Group developed and launched a community outreach activity at birth fairs to reach parents. The Alaska Birth Collaborative hosts Birth Fairs which are twice a year events in Southcentral Alaska, and EHDI Parent Leaders have had booths at the fairs to spread a positive message about newborn hearing screening and EHDI. In fall 2019, they added a birth to 3 screening focus in response to parent experiences with late onset hearing loss. A QI activity was also added to the Fall Fair to seek input from parents on newly developed posters and flyers for hearing screening. The QI project received 68 participants who voted on their favorite posters. It also encouraged conversations on positive messages regarding hearing screening. An editor from a new parent magazine visited the booth which led to a request for the EHDI Program to write an article for their online publication. This QI project has led to a recommendation, in particular from parents of children with late onset hearing loss, to expand messaging on hearing screening beyond birth to 3, to birth to 5. This will be worked on in the upcoming year. The Work Group meetings are held in-person and via Zoom to enable parents access from all regions of the state.

The EHDI Program requested and was granted HRSA carryover funds to support training and scholarship opportunities for families. These funds will be administered by SSG. The first

scholarship request is for one of the first Alaska children identified with hearing loss by the Program to attend the 2020 EHDI National Meeting with one of his parents. He resides in a small community where he is the only child of his age who is deaf, and the conference will offer the family educational opportunities not available in their home community.

The EHDI Program and WCFH partner with other agencies to leverage training opportunities for families. WCFH is collaborating with the Alaska Department of Early Education & Development (DEED) on the Preschool Development Grant Birth through Five Initiative (PDG B-5), from the Office of Child Care, Administration for Children and Families. The specific activity for the first year of the PDG is the development of a “parent as professional” training and program. The focus of the training program is on providing education for parents and other caregivers on how to be active, positive advocates, self-advocates and partners in early childhood systems. The first cohort has parents, foster parents, and grandparents from all across Alaska including Anchorage, Mat-Su, Chugiak, Kalskag, Kenai, Ketchikan, Kodiak Island, Kongiganak, Nome, Seward, Palmer, Sitka, Ft Yukon, Wasilla and Fairbanks. Some of these are parents of children who are DHH, and one is an active parent in the EHDI Advisory Committee. This “Parent as Professional” training is being developed and implemented in collaboration with the Center for Human Development (CHD), Alaska’s University Center for Excellence in Developmental Disabilities (UCEDD), and consists of asynchronous online modules, and a collaborative learning community practicum. Parents will receive honoraria for their participation in the project.

## **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 promote the EHDI 1-3-6 National Goals in Alaska. In this forum, challenges and barriers to DHH services are identified, as well as areas in which technical assistance from the EHDI Program could improve service delivery, timely diagnosis and enrollment in EI services. Issues identified in this forum generate proposals for QI activities. The EHDI Program funds Deaf Parent Navigation services through their long partnership with SSG. The EHDI Parent Navigator is a parent of children who are DHH. WCFH has had a longstanding contractual relationship with the University of Alaska-Anchorage CHD, Alaska’s University Center for Excellence in Developmental Disabilities (UCEDD). CHD also provides coordination services for WCFH for the state-sponsored Neurodevelopmental Outreach Clinic. CHD is also the home of Alaska’s the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. WCFH has also had a formal agreement to host LEND students in the Outreach Clinic. The Program will continue our existing contract with LEND program to continue collaboration on a family survey. The EHDI Advisory Committee recommended the next survey expand the focus to include more families of children who have been diagnosed with a hearing loss to better understand their barriers to diagnosis and their experience with the existing local systems of care.

Health professionals have been involved in the EHDI Advisory Committee since its inception. The American Academy of Pediatrics’ (AAP) Chapter Champion to EHDI has collaborated on past and future efforts to provide training and outreach on the 1, 3, 6 recommendations. This includes trainings for new pediatric residents and Pediatric Grand Rounds. The publication of the

2019 Joint Commission on Infant Hearing (JCIH) Statement has sparked interest in the pediatric community, and we expect to be increasing the Program's outreach plans in response to this increased attention to the EHDI goals.

The EHDI Program has built relationships with the Early Head Start (EHS) and Parents as Teachers (PAT) home visiting programs and seeks opportunities for providing education and technical assistance to these programs at meetings and conferences. EHDI also supplies Otoacoustic Emissions equipment (OAEs) to some of the Head Start (HS) and PAT programs. Recently EHDI renewed their agreement with the Cook Inlet Native Head Start Program (CINHS), a birth to 5 Native Alaskan Yup'ik language immersion program. The CINHS Family Outreach Coordinator joined the EHDI Advisory Committee. CINHS provides hearing screenings annually for their enrolled children and signed an expanded Memorandum of Agreement which includes reporting of annual hearing screenings to 3 years of age (attachment 4). During this project period, the Program wants to add more agencies to expand the number of children up to age three who are screened.

The Program also has outreached to state home visiting programs to provide education and opportunities for partnership. These partnerships provide avenues to expand hearing screening and ways to reach families that may be lost to follow-up. The EHDI Program provided Head Start programs outreach and technical guidance to introduce the National Technical Resource Center (NTRC) Early Childhood Hearing Outreach ECHO program. Some HS staff have participated in the ECHO online screener training program. As staff turnover at HS agencies occurs, the Program is exploring how to expand the usage of ECHO online training resource usage for HS agencies.

The Program is a long-term member of the Governor's Council on Disabilities and Special Education's, Early Intervention Committee. This Committee serves by statute as Alaska's Early Intervention Office of Special Education (OSEP) Part C Interagency Coordinating Council (ICC) and advises and assists the Alaska EI/ILP program.

Alaska EHDI has a longstanding relationship with the State of Alaska Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program (State EI program) and in 2019 renewed the MOU between agencies to specify communication, data- sharing and trainings to be shared between the programs (Attachment 4).

The Anchorage School District has administrative and programmatic responsibility for the statewide Alaska School for the Deaf. The School is located within three schools in the district and has representation on the EHDI Advisory Committee. Anchorage has the most culturally diverse school district in the nation with over 95 languages spoken in schools. The EHDI Program collaborates with the school and EI agencies to strategize working with families of different cultures, especially those where English is the second language.

## **Quality Improvement**

Alaska has received technical guidance on QI initiatives from our EHDI NTRC QI advisor. She provided personalized guidance on our Plan-Do-Study-Act (PDSA) projects from design, data collection, analysis, and how to present the findings in an accessible manner. Subject matter

experts from other states provided consultation. From June 2011 through September 2012, the Alaska EHDI Program actively participated in the National Initiative for Children's Healthcare Quality (NICHQ) initiative to strengthen collaboration with EHDI partners, including parents. A core team consisting of the EHDI Program Manager, the EHDI Program Coordinator (PC), 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 with input and involvement from families and community partners. To ensure ongoing QI work, the Program is currently recruiting from the EHDI Advisory Committee and other interested stakeholders to form the core QI team.

The EHDI Program will continue to focus on QI measures through the following aims. Sectors needing improvement will be identified and driven by data analysis.

AIM/IMPACT 1: To maintain a 95% screening rate of the number of infants that complete a newborn hearing screen no later than 1 month of age by March 31, 2024.

AIM/IMPACT 2: To increase to 38% the number of infants that complete a diagnostic audiological evaluation no later than 3 months of age by March 31, 2024.

AIM/IMPACT 3: To increase to 40% the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age by March 31, 2024.

AIM/IMPACT 4: Increase by 20% from baseline the number of families enrolled in family-to family support services by no later than 6 months of age by March 31, 2024.

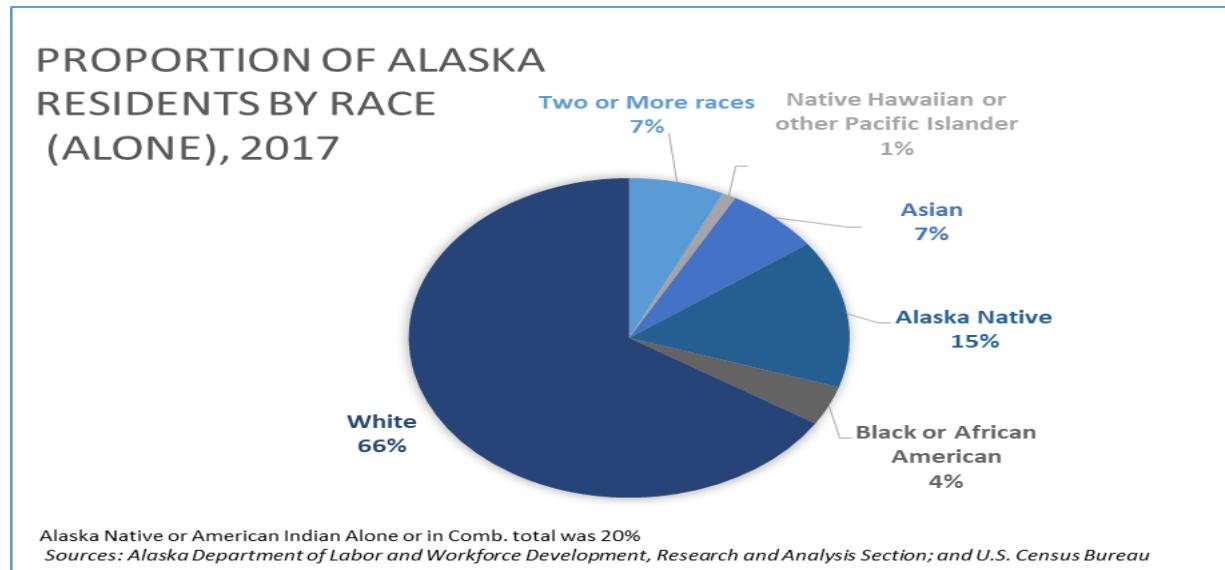
AIM/IMPACT 5: Increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age by March 31, 2024.

AIM/IMPACT 6: To increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program by March 31, 2024.

## **NEEDS ASSESSMENT**

Two defining characteristics of the state of Alaska are: 1) expansive physical geography and 2) the racial and ethnic 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 people per square mile. This is the lowest population density of any state. The 2017 Alaska population was estimated at 737,080 (Alaska Department of Labor and Workforce Development, 2017). The State has been experiencing a high outward migration rate, which is particularly high for 18-to-35-year-olds and their children younger than school age. While Alaska's total population increased 4% from the 2010 Census to July 2017, children under the age of 5 decreased 3% from 53,996 to 52,398. This age group currently makes up 7% of the state's population. The number of children in the under 5 age group is volatile because migration has a large effect on it, and the number of births in Alaska has been declining over the past few years. In 2017, there were 10,447 births. In 2017, 16% (114,702) of Alaska residents were 25 to 34 years old. In 2010, 15% (103,125) of Alaska residents were in this age group. Alaska has historically experienced strong net migration gains of people aged 25 to 34 (Alaska Department of Labor and Workforce Development, 2017).

Only three cities in Alaska have more than 10,000 people – the Municipality of Anchorage (300,549), the City and Borough of Juneau (33,026), and the City of Fairbanks (31,721). These three areas are home to 50% of Alaska's population. Approximately 59% of people living in Alaska are migrants to the state. Of those who dwell in rural areas, the majority are Alaska Native people. Alaskans of Hispanic origin made up 7% of the total population.



Almost 85% of Alaskan communities, including the state's capital city of Juneau, are not connected to the road system. Accessing primary or specialized health care often requires travel by commercial jet, small plane, the state marine ferry system, all-terrain vehicles, small boats or snow machines. Some Alaska residents may travel in-state distances equivalent to traveling from Washington, D.C. to New Orleans for even routine medical care. Alaska has limited pediatric specialists and many families must travel out of state for diagnosis and treatment. In 2019, Alaska also began a trend of existing pediatric specialists moving out of state. The WCFH Section Chief serves on the Board of the All Alaska Pediatric Partnership, and this organization has made this issue a critical priority given the decrease in services that occurred in 2019. Additionally, severe weather can render travel impossible, creating especially critical situations in medical emergencies. Expensive travel and lodging also increases the overall costs of health care in Alaska.

Health care delivery in Alaska consists of three separate systems: private, tribal and military. 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 (ANMC) in Anchorage. Funding for the consortium is the product of several sources including federal Indian Health Service, Medicaid, private insurance, and tribal consortium dollars. Another system of care includes private, non-profit and for-profit secondary and tertiary care hospitals and private health care providers including nurse practitioners, physician assistants and physicians. The third system is the extensive military system supporting the active duty and retired armed forces. Alaska has a high percentage of military residents and is home to various

Army, Air Force, and Coast Guard bases, as well as many National Guard units. Both the tribal health system and the military system incorporate the Patient-Centered Medical Home (PCMH) model of care throughout their systems. More private practices have begun to work towards this model as well. There is also a system of community health centers, including those that are federally-qualified, throughout the state.

The geographic isolation of rural communities means significant challenges in assuring all populations have access to routine preventive, acute medical, and specialty care. Pediatric specialty care, even in urban areas of the state, is quite limited. For example, the only Level III neonatal intensive care unit is located in Anchorage. Many communities have no facilities equipped for childbirth, so pregnant women must leave their homes at 36 weeks gestation to deliver in a regional hub community or Anchorage. Consequently, more than half 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. Since audiology follow-up may not available in the rural communities, the EHDI Program worked with ANMC to change this process. Currently, for infants being discharged to a rural, remote home location, the hospital labor and delivery staff put a medical hold on travel so that the child can receive a diagnostic audiology assessment before discharge. Since the trend continues to be more deliveries occurring in Anchorage, rather than the smaller, rural hospitals, the practice of audiology follow-up prior to discharge will continue to be encouraged. Recruiting and retaining primary health care providers and allied health professionals, such as audiologists, in rural areas continues to be a major barrier to providing health care services.

## **Disparities**

The largest differences in health status are between the Alaska Native and non-Alaska 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 continues to be poorer than that of non-Native people in several domains. Living in remote communities with high unemployment rates and low income, as well as numerous other social barriers to accessing health care services are contributing factors.

Health care services are also difficult to deliver in rural Alaska due to high transportation costs and the 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 rural village clinics to provide basic health care services and referrals. Often they are the only point of contact for medical issues, as there is most often not 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 EHDI.

When infants are born at regional tribal hospitals located in rural/remote parts of the state, the family may have traveled far to receive medical care. Travel for the birth often happens by a combination of methods including small plane, boat, or all-terrain vehicles. Only two of those regional hub facilities have an audiologist on staff, with non-sedated pediatric diagnostic evaluation is available. The audiology department at ANMC in Anchorage travels to five of the seven tribal regional hospitals for scheduled clinics. Follow-up testing and diagnosis by an

audiologist can be delayed due to weather and flight interruptions for the traveling audiologist or the parent. These weather delays can sometimes create delays of months for infant re-screening and diagnostic assessment in Anchorage.

## **Alaska EHDI Data**

Data indicates the percentage of all Alaskan infants receiving hearing screens rose from 95% in 2009 to 96% in 2018. This statistic includes all infants born in Alaska. In birthing hospitals, 99% of infants are screened. More families are choosing to deliver outside of the traditional hospital setting. In 2013, the percentage of OOH births was 6%, and preliminary 2018 data suggests it is risen to 7% (EHDI-IS). This rate, the highest in the nation, accounts for the continued discrepancy between the total number of newborns screened and the number of in-hospital births screened. Since diagnosis and referral are still dependent on timely newborn screening, the program continues to focus on engaging midwives and birthing centers to help improve screening rates. A Nurse Midwife joined the EHDI Advisory Committee in 2016.

The screening rate for OOH births has dramatically increased from 37% in 2009, to 68% in 2018. This population continues to account for 94% of missed newborn hearing screens (EHDI-IS). To help further increase the screening rate, the EHDI Program placed screeners in six of the largest midwifery centers, as well as two public health nursing centers. The Program has continued training and outreach to midwiferies, and as a result, two additional midwiferies have purchased their own hearing screeners in 2018 and 2019. The Program anticipates the screening rate for the OOH population will increase in 2019. Strategies for improvement include the additional availability of screeners, early letters encouraging screening sent to OOH birth families and outreach to midwiferies, birth fair attendees, and PCPs.

In the next grant cycle, the EHDI Program will continue to identify facilities with missed screens and help them improve their rates of making an audiology diagnostic appointment after referral by utilizing change strategies within the newborn nursery. Program activities will be able to focus more on timely diagnostic and intervention improvements as Alaska's overall newborn hearing screening rate remains very high.

The Maternal Child Health Epidemiology Unit (MCH-Epi) completed a data analysis linking EHDI data with birth certificate data from the Section of Health Analytics and Vital Records (HAVRS) to examine the demographics of children who were diagnosed with hearing loss born in 2016 to 2018. It was found that infants with hearing loss (bilateral, unilateral, or unspecified) did not differ significantly from infants with no hearing loss on maternal education level, race, Medicaid eligibility, residential census area, Kotelchuck index of prenatal care utilization, gender and maternal age. Data regarding health literacy and sexual orientation are not available. Children who were loss to follow up were more likely to be beneficiaries of Medicaid.

The MCH-Epi Unit also conducted an analysis of the EHDI and Alaska Birth Defect Registry (ABDR) data. Record linkage was performed based on personal identifiers (child name, child date of birth, mother's name). Probabilistic matching, which allows for variation between pairs to be quantified and scored, was used to identify potential matches. Various methods exist to evaluate matches. Here, a Jaro-Winkler method that identifies the number of elements in

common was used score each pair. Potential matches were inspected manually and all matching was done using the R statistical software. This match process identified 6 children for birth year 2018 who had received an audiology examination and diagnosis but were not reported to the EHDI-IS. The agencies who diagnosed the childre were contacted by the EHDI program staff to offer technical guidance on reporting. The program will continue the data match and anticipate this activity will continue to reduce loss to follow up rates.

## Audiology Capacity

The availability of audiologists specializing in pediatrics in Alaska has been increasingly challenging and the loss of capacity is reflected in all three separate systems for health care. In the military system at the two joint Army/Air Force bases located in Fairbanks and Anchorage, the audiology clinics provide outpatient screening though they no longer conduct pediatric audiology exams. They prefer to refer off base to pediatric audiology. The support staff on military bases conduct tracking and follow-up duties. Frequent turnover among audiologists, support staff, and newborn nursery staff remains challenging. The EHDI Program continues to collaborate with new military personnel. The EHDI Program worked with one military base to deploy QI strategies to reduce loss to follow up. Close communication with the EHDI Program and military partners during this grant cycle led to the identification of two military dependent children in remote postings who were diagnosed with hearing loss following a newborn hearing screening. Due to the remote location of the family's posts, both families were transferred to an urban base location that had the appropriate diagnostic and intervention services necessary for an infant diagnosed with hearing loss. The EHDI Program will continue to collaborate closely with this health system.

Central audiology services for the tribal health system are located in Anchorage at the Alaska Native Medical Center (ANMC), with audiologists also located at a regional hub medical facility in Nome at the Norton Sound Health Corporation (NSHC). Since 2016, three additional regions lost the capacity to provide pediatric audiology services. This meant that children residing in these remote locations who refer must be flown into Anchorage for audiology follow up. Children who are tribal beneficiaries from all regions of the state must be flown to Anchorage for diagnostics requiring sedation. Due to recent delays and increased waits times for an audiology appointment, the ANMC audiology clinic has hired additional audiologists. It is expected that this increase in hiring will reduce wait times for an appointment. During this grant cycle, audiologists were hired for the Bethel region with the support of the EHDI Program. During this upcoming project period, the WCFH Section Chief and EHDI Program Manager will continue communication with Maternal Child Health leaders at ANMC to monitor and strategic this workforce challenge.

In the private sector, children are generally referred to Anchorage for diagnostic assessment. A private practice audiologist located in Juneau travels to Ketchikan and Petersburg. In the Kenai Peninsula, an audiologist can screen children and do visual response audiometry. Fairbanks also has the capacity to do sedated ABRs. Parents must drive long distances on the Kenai Peninsula or fly to Anchorage from Juneau, Ketchikan, or Petersburg for a complete diagnostic work-up and hearing aid fittings. Many families in southeast Alaska need to travel to Seattle. While Medicaid does support air travel expenses for Medicaid-eligible services, private insurance does

not always cover the cost. Approximately half of Alaska's children are Medicaid-eligible. During 2016-2018, there were Medicaid payment challenges that resulted in one region of the state not accepting any pediatric patients for several months. The payment issue with Medicaid was resolved in 2019 with the leadership of the EHDI Program Manager. The availability of pediatric audiology clinics has stabilized at service levels similar to before the Medicaid payment issue was encountered. Since all the private practice audiology clinics have enrolled in EHDI Pediatric Audiology Listing Service (PALS), this provides a referral listing services of birth facilities, care coordinators and primary care providers to use when they are following up with a child who referred on their screening.

The ANMC has the capacity to do cochlear implants, and private sector families in the Southcentral region can receive a cochlear implant in Anchorage. In the Southeast Region however, private sector children still fly to Seattle for implants. Implant mapping is only administered in Anchorage. 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 nor have tribal health benefits.

The EHDI Program is keenly aware of the barriers to timely diagnosis by audiologists, and is always looking for additional strategies for improvement. The primary barrier to timely diagnosis has been identified as scarcity of providers. The extreme shortage of pediatric audiology services statewide from 2016 and 2018 resulted in five regions losing their pediatric eulogy staffing. Pediatric audiology centers are currently located in only four communities in Alaska: Anchorage, Fairbanks, Bethel and Nome. Both the tribal health system and the private sector continue to recruit for audiologists; however, the profession remains a scarce commodity in Alaska leaving some clinics understaffed with wait times for an exam. Families that must be flown to the regional clinics from more remote locations face barriers ranging from costs to weather, and this has an impact on the "no show" rates. When families are able to attend a clinic, children are often re-screened or may be older and have middle ear effusions or infections. This reduction in capacity had a negative impact on the rates of children receiving a diagnosis after a hearing screening by 3 months of age and the rate decreased to 34%. These regional disparities account for a large portion of the state's late diagnosis and loss to follow-up, and will continue to be an emphasis for QI strategies and implementation of known best practices. EHDI Program staff continue to be conveners and communicate with health systems to coordinate efforts to mitigate these barriers.

While a statewide shortage of audiologists in all systems and regions is a daunting challenge to mitigate, the program had some notable success in expanding capacity. The Yukon-Kuskokwim Health Corporation (YKHC) region, a sparsely populated rural area the size of Louisiana, is not connected to the state highway system. The medical hub, located in Bethel, serves 60 small communities and villages. In 2018, the EHDI Program met with stakeholders in the region, and held training and listening sessions to hear what stakeholders in this region thought might be possible solutions to help increase timely follow-up rates. The region had been without a resident audiologist for three years. After the visit, the region was able to recruit two audiologists and an audiology technician and opened a new clinic building in 2019. This region is now staffed, equipped and will be utilizing Plan-Do-Study-Act (PDSA) cycles to improve diagnostic timeliness for their region. The new audiologists, labor delivery nurse manager and clinical

educator will be utilizing online hearing screening trainings from EHDI NTRC to train nurses to reduce the referral rate. The region is trialing a new PDSA for timely diagnosis. If a baby will be released to fly home to a remote region, the on-call audiologist comes directly to the hospital to perform a screening, and if needed, an assessment, before the child flies home. They have a pager, and the plane will be held while the tests are conducted. In Anchorage, ANMC Audiology, which employs audiologists that travel across the state to provide pediatric audiology services for 90% of the state's Alaskan Native children, is now fully staffed at nine audiologists. It is expected that this expansion of audiology availability in the Alaska Native tribal system will have a significant positive impact on the timeliness of diagnosis within the tribal healthcare system during this cycle.

The EHDI Program is also excited to partner with NSHC which is now fully staffed at 5 audiologists and are continuing their successful tele-audiology practice. The NSHC Audiology Manager and the EHDI Program Manager presented an instructional session at the 2019 EHDI Annual Meeting. The NSHC Audiologist presented virtually to the audience from Nome and utilized the NSHC tele-audiology system so the attendees could witness the functioning of the system first hand. This presentation has led to sharing the experience of tele-audiology with other states, the EHDI program, and the statewide tribal health system. The program will be involved in exploring expanding teleaudiology practice to other regions of the state.

### **Referrals and Enrollment into Early Intervention/Infant Learning Program (EI/ILP) Services**

The EHDI program (along with other CYSHCN programs) have regularly collaborated with the EI/ILP leadership and both are excited about the possibilities for improvement and data sharing. These include improving the referral process for partners and providers to EI/ILP and jointly examining the reasons why families decline EI/ILP services. Since July 2016, the EI/ILP office has been giving named data to the EHDI Program, a success after many years of working on this effort. The EHDI Program Manager is now attending EI/ILP grantee meetings, along with other WCFH staff, and presents on EHDI twice a year. In 2019, a new MOU was signed between the EHDI Program and the Alaska EI/ILP program (Attachment 4). The agreement defines communication, training, referrals, and/or data sharing between the State EHDI Program and the Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.

## **METHODOLOGY**

### **A. Lead efforts to engage all stakeholders in the state/territory EHDI system to improve developmental outcomes for children who are DHH**

The EHDI Advisory Committee and sub-committees are key to utilizing diverse stakeholders statewide in efforts to improve the Alaska EHDI system. The Advisory Committee was established in 2002 and meets a minimum of three times per year to promote the EHDI 1-3-6 National Goals. The Committee has proven to be an effective method of increasing health professionals' engagement with and knowledge of the EHDI system and was instrumental in getting the necessary legislation passed to implement universal hearing screening in Alaska. The Committee, includes parents and self advocates, creates opportunities to improve family

engagement, partnership, and leadership within the EHDI Program and systems. In the past, volunteers from the Advisory Committee have participated on the QI team and will participate in the QI team for this grant cycle.

A factor in selecting members for the Advisory Committee is their capacity to represent statewide populations. Representatives from the ANTHC are located in Anchorage but travel to, and are familiar with issues that affect remote regions of the state. Members also include State representatives from Public Health Nursing and EI/ILP that also provide services on a statewide level. Audiology representatives include those from the private, tribal and military health systems. Birth screeners, neonatologists, and otolaryngologists are also part of the committee. The AAP EHDI Chapter Champion has been active in the program since 2017 and is a neonatologist at the largest NICU in the state. The diverse statewide membership provides many opportunities for outreach throughout the state. Stone Soup Group (SSG) is a 25 year old statewide parent advocacy organization based in Anchorage. The EHDI Program has also conducted outreach to ensure there are parents representing different communication choices. Parents/family members of infants/children who are DHH comprise 25% of the current membership. The Advisory Committee has strong family members who partnered with the EHDI team in the HRSA Family Leadership in Language and Learning Center (FL3). FL3 has been a great resource for the EHDI program to access trainings and resources which address family engagement, leadership, and partnership. To further support family leadership trainings, the EHDI program amended the agreement with SSG to add family training and scholarship funds.

### **The organizational makeup of the EHDI Advisory Committee:**

- Alaska Center for Ear Nose and Throat- Audiologist
- Alaska Chapter of AG Bell
- Alaska Chapter Hands and Voices (Start-up Chapter)
- Alaska Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program
- Alaska Native Medical Center- Tribal Health Audiologist
- Alaska Native Medical Center- Nurse Manager, Labor and Delivery
- AAP Chapter Champion - Neonatologist
- Alaska State School for the Deaf and Hard of Hearing
- Early Head Start
- Family Delegate- Association of Maternal and Child Health Program (AMCHP)
- Family to Family Health Information Center-Stone Soup Group
- Geneva Woods Birth Center - Certified Nurse Midwife
- Geneva Woods - ENT physician
- Governor's Council on Disabilities and Special Education Early Intervention Committee (expertise in addressing diversity, health equity, and cultural competency)
- Hope Community Resources Deaf Navigator Program
- Joint Base Elmendorf-Richardson- Military Audiologist
- Northern Hearing Services – Private Sector Audiologist
- Program for Infants and Children (EI/ILP grantee) - Speech Language Pathologist
- Program for Infants and Children (EI/ILP grantee) - Teacher for DHH
- Programs for Infants and Children (EI/ILP grantee) – Executive Director

- Providence Alaska Medical Center- Private Audiologist
- Providence Alaska Medical Center- Birth Screening Supervisor
- Special Education Service Agency- Education consultation for low incidence disabilities
- State of Alaska - Children & Youth with Special Health Care Needs (CYSHCN) program
- State of Alaska - Maternal, Infant, & Early Childhood Home Visiting (MIECHV) Program Manager and Alaska CYSHCN Director
- State of Alaska Medicaid Agency
- State of Alaska EI/ILP Part C of the Individuals with Disabilities Education Act (IDEA)
- State of Alaska Title V Maternal Child Health Director and Section Chief
- Parents (10)
- DHH adults (2)

In the Advisory Committee meetings, challenges and barriers to services are identified. Data from the EHDI Program is shared and discussed at each meeting. Issues identified in this forum have generated proposals for QI, and members can participate in QI activities. During the first two months of the grant cycle, commitments from volunteers from the Advisory Committee will be sought to join, or continue on, the QI team. This will help meet the goal of completing an assessment of current partnerships and identify new partners who can address gaps in the EHDI system. The Advisory Committee will also be key to helping the Program address diversity and inclusion in the EHDI system.

To supplement the expertise of the current Advisory Committee, staff from the state's largest EI/ILP service program, located in Anchorage, will be recruited for participation on the QI team. This grantee agency has highly skilled EI/ILP service professionals who have expertise in hearing loss and the spectrum of communication modalities, and who can inform families of all available opportunities. In addition, family members who may not have previous experience with QI processes will be recruited. Family members without previous QI experience will be contacted by the EHDI Program Manager, either in person or by phone, to help them envision what the QI process involves, answer any questions, and emphasize the value of their input to the process. The core QI team will inform the PDSA cycles and provide input and expertise to the EHDI Program. The core QI team will not be responsible for carrying out these PDAs, but rather will monitor and advise the individual efforts. PDAs will be conducted in collaboration with staff from the core partners (e.g. EI, Stone Soup Group, audiologists, tribal health, etc.) who will collect data and report on their work to the QI team.

The projects will be aligned with the overall program goal:

**To support the development of statewide programs and systems of care that ensure that deaf or hard of hearing infants, and young children up to 3 years of age receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI) that optimize their language, literacy, and social-emotional development.**

To succeed in the goal stated above, the EHDI Program will implement data-driven and targeted strategies for improvement, through the following aims.

**AIM/IMPACT 1: To maintain a 95% screening rate for infants completing a newborn hearing screen no later than 1 month of age by March 31, 2024.**

*Objective/Outcome 1.1: By March 2024, 65% of all newborns who did not pass, or who did not receive their newborn hearing screening, will have a rescreen and/or audiology appointment by one month of age.*

Demographic data and newborn hearing screening results (missed, passed and referred) are entered into the EHDI-IS by all of Alaska's eighteen birthing hospitals, six midwifery centers, and two public health centers. Consistent, timely and accurate data entry ensures that complete and clean data is available in the EHDI-IS for follow-up activities, including measuring tests of change. The EHDI program utilizes reporting features on the EHDI-IS for surveillance, and directly contacts facilities to correct missing or incomplete information. The Program has received feedback that the current quarterly performance report is not easy to read or is not intuitive when deciding on the next action needed. The Program has researched best or evidence-based practices in providing hospital feedback from other states. To incorporate the findings from this research, a new birthing facility report card will be created to replace the practice profiles, with clearly communicated performance benchmarks. The EHDI Program has also consulted with our EHDI-IS contractor and has created a plan to do ad hoc improvements to the system, so the creation of the hospital report card will take less staff time to produce than the current less effective practice profiles.

The OOH birth population in Alaska continues to be a very high with 7% of the total births occurring outside of the hospital. To provide early outreach to this population, the EHDI Research Analyst (funded by CDC) completes a match of EHDI-IS and HAVRS data weekly and provides the Program Coordinator a list of OOH births that are not in the EHDI-IS. This match and list process enables the Program Coordinator to update the EHDI-IS data and to send timely letters that contain a positive message regarding newborn hearing screening. The letters also contain information on the availability of newborn hearing screening in the community to families that had an OOH birth and no record of hearing screening. The deploying of these letters to OOH families has contributed to raising the screening rate for OOH to 68% in 2018 and in maintaining the high overall screening rate of 96% statewide, despite the high OOH births in Alaska. Outreach efforts to the OOH birth population continues to be a valuable activity of the EHDI program since the significant number of OOH births disproportionately impacts the number of unscreened children each birth year. For example, in 2018, the OOH birth population was 7% of the total birth population yet they comprised 94% of all the missed screenings statewide (source: 2018 HAVR and EHDI-IS data).

**AIM/ IMPACT 2: To increase to 38%, the number of infants that have completed a diagnostic hearing evaluation no later than 3 months of age by March 2024.**

*Objective/Outcome 2.1: By March 2024, 38% of all newborns who did not pass their newborn hearing screen will have an audiology appointment by three months of age.*

The starting point in achieving the 2.2 objective regarding timely diagnoses begins at the birthing facility when the child receives a referral, or when the facility sets up an appointment for diagnostic assessment. As part of regular monitoring, the Program Manager will contact the birth facility on the status of their follow up efforts and request any updates to be made in the EHDI-IS. Data reports on children who were referred for a diagnostic assessment but have not received that assessment. are used to create mailing lists and letters for notifying parents and the child's PCP on the need for follow-up and the prudence of seeking a diagnosis as soon as possible for the best developmental outcomes. This communication with the PCP incorporates the medical home concept by providing information so the PCP can coordinate care with the family. If no PCP response is received, the Program Manager will contact the PCP clinic by phone to request an update, encourage follow up, or offer resources.

### **AIM/IMPACT 3**

**To increase to 58% the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age by March 31, 2024.**

*Objective/Outcome 3.1:* To identify the three most common barriers to EI/ILP enrollment for DHH infants and their families by March 31st 2024.

In 2019, the EHDI Program contracted with the CHD to develop and administer a Parent Survey. A follow-up survey has been updated to include additional families of children diagnosed with hearing loss so that the survey can collect information from families to better understand barriers or reasons for non-enrollment in EI.

Improvement activities will be measured through data reports from the EHDI-IS to identify effective strategies and evaluate results on an ongoing basis. Quarterly reports will be shared with the EI/ILP program, QI team, and Advisory Committee, and adjustments to adapt, adopt or discard strategies will be made based on the trends identified in the data. Changes showing positive results will be expanded and tested on gradually larger scales over time, until the team is secure in the knowledge that changes could be implemented system wide. The EHDI staff will develop and implement a standardized protocol that incorporates data and the effective strategies developed from QI measures. The team will continue to monitor the data quarterly to assure that the improvement is maintained.

After statewide implementation, the rates of diagnosed children receiving a referral to EI/ILP by three months of age will be regularly compiled and reported to the QI work group. If the rates are not increased and meet the aim, then new strategies to change the rate of timely diagnosis will be researched. Strategies that have proven successful in other state EHDI programs will be considered. When the strategy that has the most likelihood of success is identified, it will be trialed using PDSA methods. Results and outcomes will be shared at the statewide with EI/ILP grantees, the Advisory Committee and other partners.

### **B. Engage, educate, and train health professionals and service providers in the EHDI system.**

**AIM/ IMPACT 6: To increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program.**

*Objective/Outcome 6.1: By March 2024, three trainings will be offered to health professionals and service providers trained on key aspects of the EHDI Program.*

The EHDI Program plans outreach and educational presentations for health professionals on:

- The 1-3-6 recommendations and the importance of timely screening, diagnosis, referral, and enrollment into EI services.
- The need for hearing screening up to age three to identify, diagnose, and enroll into EI those infants who pass a newborn screen but later develop hearing loss.
- The benefits of a PCMH approach and family engagement in the care of a DHH child.
- The importance of communicating accurate, comprehensive, up-to-date, evidence-based information to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communications modalities, as appropriate.
- Joint Committee on Infant Hearing (JCIH) 2019 Position Statement
- The Alaska CHD Parent Survey Results

The Alaska AAP Chapter Champion continued in her role even after funding for the position was lost. She has utilized presentation templates and other resources from the HRSA-18-069 National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH) for presentations to medical residents and at Pediatric Grand Rounds. She has two EHDI presentations planned for the upcoming grant cycle - Pediatric Grand Rounds and the All Alaska Pediatric Partnership Pediatric Symposium. The newest CHD Parent Survey will be the basis for a presentation by the EHDI Program Manager, a Family Leader and CHD research staff. Having a parent present with the Program Manager has been effective in the past. The practice of having parents present to providers will continue. Family Leaders are often willing to share their personal story and these stories reinforce the urgency in following the recommended 1, 3, 6 guidelines for the best outcomes. The EHDI Advisory Committee now has two parents that have children who were diagnosed with late onset hearing loss. These parents are passionate in communicating the message of regular hearing screenings until the age three. Family Leaders are planning presentations on the importance of birth to three hearing screenings to EI/ILP staff and Head Start providers. The Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) is a recipient of the HRSA-16-190 Pediatric Audiology Competitive Supplement to LEND, and have placed audiology students in Anchorage for practicum experiences. URLEND is exploring placing another student in Alaska next year. They have a program in tele-audiology, and the EHDI Program has previously utilized their resources when starting the tele-audiology program in Alaska.

The Advisory Committee identified a need for accurate and attractive educational materials to be placed in medical provider offices as an important way to reinforce the positive message on the benefits of hearing screening up until age three. The 2019 Parent Survey identified barriers to diagnosis. The primary barrier identified was that parents believed they could know their child can hear without follow up testing. This barrier was addressed as a QI plan was developed to

help create materials promoting the benefits of hearing screening up to age 3. A first draft set of posters and flyers was created using Alaskan family photos that were tested for content and layout at a birth fair in the Mat-Su Borough. Fair participants enjoyed looking at and scoring their favorite poster, and it was found that the posters were useful in engaging parents and other family members in conversations around the benefits of hearing screening. After the team met to review the QI project results, it was decided in the next cycle to proceed to recruit additional collaborators to create educational materials:

- Positive, attractive, culturally-informed, medically accurate, messages
- Memorable messages that resonate with parents
- Video or audio messages
- Other avenues for distribution

FL3 and The Family Leadership in Language and Learning (FL3.) and the EHDI National Technical Resource Center (NTRC) have agreed to collaborate on the project in the upcoming grant cycle by providing feedback on the flyers and posters. Family Leaders will continue to test the messages developed through this collaboration at local Birth and Children's Fairs, Community Baby Showers, social media and other venues as identified by families.

During the upcoming grant cycle, the team will distribute the created posters, flyers and electronic messages at pediatric and obstetric offices, WIC, Public Health Nursing offices, home visiting programs, the EHDI website, DPH website, Department Facebook page, and other locations as identified by the project participants.

**C. Describe strategies to strengthen the capacity of to provide family support and engage families with children who are DHH as well adults who are DHH throughout the EHDI system**

AIM/IMPACT 4: To increase by 20% from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age by March 31, 2024.

Objective/Outcome 4.1: All parents with a DHH diagnosed child will be offered Stone Soup Group (SSG) parent navigation services by March 2024.

The EHDI Program has had a grant and partnered closely with SSG, Alaska's Family 2 Family grantee, for more than 15 years. The first year of the grant cycle will be the baseline to measure improvement. A SSG Parent Navigator is dedicated to the EHDI Program, and provides support, assistance with the system of services, and information to families diagnosed with hearing loss.

To increase the impact of the SSG parent mavigation services, the EHDI Advisory Committee and EHDI team will work closely with SSG to analyze the 2019 EHDI Parent Survey results to better understand why families may decline parent navigation services, and to also better understand referral resources. With technical guidance from FL3, SSG and EHDI will research evidence-based strategies to increase the number of families that receive family-to-family support. When a potential strategy is identified, the team will develop and conduct a PDSA cycle with SSG. EHDI-IS data will be used to evaluate the results, and if necessary, the strategies will be adapted and a new cycle of change will be conducted. SSG, EHDI, and the QI team will share

data from the PDSA with the Advisory Committee and identify the next cycle. The team will develop and implement a standardized protocol with SSG that is data-driven and employs effective strategies identified through the QI process. Results will be disseminated and discussed with SSG during quarterly meetings between EHDI and SSG staff.

**Objective/Outcome 4.2:** By March 31, 2024, one Parent Survey will be conducted to gather information from the families of children who were referred for follow up on their newborn hearing screening and did not receive the recommended follow up..

The EHDI Program Manager will meet with the CHD staff at the onset of the project. The agenda will be developed with input from both agencies. The projects that are planned for this coming grant cycle include:

- The CHD program will conduct another parent survey, using parents of DHH children as survey takers, to better understand the reasons for loss to follow-up in the 1, 3, 6 steps of the EHDI process.
- CHD will present a summary of the finding to the EHDI Advisory Committee.
- The LEND Family Advisory Council (LFAC), a parent committee sponsored by CHD as part of Alaska's LEND program, will conduct a parent training on DHH in collaboration with EHDI program.
- During LEND presentations on early childhood screening and diagnosis, the need for hearing screening and what it means for development and how it impacts intellectual and developmental disabilities (IDD) will be discussed.
- Information related to DHH will be included in the LEND curriculum for Alaska.
- A LEND fellow will conduct a project focusing on the DHH population.
- LEND will conduct a session on hearing loss and screening.

During quarterly contract meetings with CHD, updates on progress towards program goals and financial status will be provided and any changes to the work plan will be discussed. Annual progress will be documented in the meeting minutes. This will be shared with the EHDI Advisory Committee and also shared at the Annual EHDI meeting.

**AIM/IMPACT 5:** To increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age by March 31, 2024.

**Objective/Outcome 5.1:** By March 2023, 65% of Families with a diagnosed DHH child under 9 months old will be offered enrollment in DHH peer support services.

SSG does not currently have a DHH Guide program, and they will be consulting with FL3, EHDI-NTRC and other states and territories regarding best practices for a program. FL3 will be a resource for DHH Guide program participants. The SSG EHDI Family Navigator has been with the program for many years and has traveled to provide outreach and resource development to the surrounding regions. Drawing on this experience, she will be able to use the many contacts she has formed statewide to recruit DHH Guides. FL3 will collaborate and provide technical guidance on the best practices and evidence based trainings and resources for the DHH guide program to base expansions plan. The local chapters of AG Bell, the startup Chapter of Hands and Voices, and Advisory QI team members will work to incorporate professional development

and culturally informed practices in the expansion. The EHDI staff will expand the honorarium policy to include DHH Guides. Once the DHH Guides are recruited and trained, the EHDI-IS will be utilized to locate the families who have received a diagnosis, but have not yet been offered DHH guide/peer support. Community events for families can serve as meeting locations where Guides and families can meet in the community. For families in remote communities, how to best offer DHH guide will be explored. Local resources in remote communities will be identified and consulted to recruit DHH adults who are willing to attend trainings and provide guide services. Local elders and providers will be consulted to assure that the program operates in a culturally informed manner in remote communities. Services may be offered in-part by utilizing a virtual platform. Families may be able to connect with a DHH Guide when the family travels to a larger community to receive medical and audiological care.

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**D. Describe methodologies to assess the current status of coordination across early childhood programs and develop a plan to improve coordination of care and services for families and DHH children.**

In Alaska, we do not have a unified “Department of Early Learning” or “Department of Early Education and Care”, the way many other states do. Our 0-5 programs rest in multiple divisions, primarily under two State departments; the Department of Health and Social Services (DHSS) and the Department of Education & Early Development (DEED). Both departments use state and federal funds to support and develop a mixed delivery system to increase early childhood program quality and improve child outcomes. The Alaska Early Childhood Coordinating Council (AECCC) is co-chaired by the Commissioners of DHSS and DEED and is convened to “support the creation of a unified, sustainable system of early care, health, education, and family support for young children and their families.” The MCH Title V Director and WCFH Section Chief is one of the organizers of the AECCC and the Perinatal Manager is also an active member through her role in MIECHV. These two personnel will ensure that EHDI is considered and is linked with other programs and initiatives of the Council.

There is a strong movement in the state to remove silos in systems and to build a more comprehensive early childhood system of care, including care and services for families and DHH children. Challenges in barriers to services, workforce recruitment and retention, high costs, insufficient funding, and the complex lives of Alaskan families affect all early childhood programs, including EHDI. Currently the Alaska early care community is focusing an intense effort on assessing early childhood systems across programs and developing plans of coordination and improvement. Leveraging a variety of state, federal, public and private funding, the Alaska early childhood community is in midst of conducting a statewide 0-5 needs assessment and an environmental scan of services. This work will provide current information and data on availability, quality, accessibility, costs and barriers in early childhood programs. These assessments will lead to the development of an early childhood strategic plan, with input from multiple care, education and health programs. One anticipated outcome will be to remove some of the barriers to data sharing among systems, potentially leading to a unique child identifier that can follow a child from birth to school age. All of this work to assess, evaluate and improve early childhood systems will have a direct impact on the multiple programs and

providers that intersect with families of DHH children. WCFH is an active partner in all these efforts.

To ensure the parent voice is heard in these conversations and to increase parent knowledge and choice, WCFH is using Preschool Development Grant (PDG 0-5) funding to develop and implement Parent Engagement Training. This training includes asynchronous, online modules and a collaborative learning community. The EHDI Program Coordinator is leading this project, and several parents of young children are enrolled in the first cohort due to launch in November 2019. Plans are to continue this training if second year funds become available. To further incorporate the parent perspective, the CHD Parent Survey will be expanded this year to include more families of children who are diagnosed with a hearing loss to better understand the benefits and barriers early childhood programs for these families.

Help Me Grow (HMG) is a national model designed to support families so all children develop to their full potential. In January 2018, Alaska launched Help Me Grow-Alaska (HMG-AK) in three pilot communities, with funding from the WCFH Early Childhood Comprehensive Systems grant (ECCS). In 2019, it expanded statewide and has diversified its funding sources to move toward independent sustainability. HMG-AK is a free service and is open to all Alaskan families, and intended to be a resource for anyone caring for children, including medical and child care providers. It is a support for navigating the complex mental and physical health care systems, and it will serve a single access point for connection to services, social supports, developmental screening and educational resources. The system HMG-AK is helping to build goes beyond connecting children to services. The goal is a more connected and cooperative system that operates from both grassroots to leadership in order to support anyone caring for children and their families. This includes children who are DHH and their families, who need not only screening and evaluation resources, but a wide array of supports on services depending on the individual needs of the child and family.

## **E. Additional Items**

The budget narrative includes a funding request for the EHDI Program Manager and parent to attend the required EHDI conference each year of the grant cycle.

As mentioned in the methodology, the Program is committed to partnering with the FL3 Center, the EHDI NTRC, LEND, and the PFCMH in this work plan.

## **Sustainability**

Alaska legislation mandates insurance coverage for hearing screening within 30 days of birth. If a newborn is referred for a diagnostic assessment, it is a service covered by insurance. All birthing facilities in the state are doing well screening infants, with the screening rate for hospitals at 99%. All facilities with screening equipment and audiologists administering diagnostic evaluations are required to report into the EHDI database. WCFH also receives federal funding from the CDC that supports the database contract and funds a percentage of the personnel costs for the EHDI Program Manager, Project Coordinator, and Research Analyst I positions. The remainder of personnel costs to support EHDI come from State General Funds

Funding from this HRSA grant will be used to continue and expand agencies that provide support to families/parents/caregivers of newborns and infants who are DHH. Additionally, the HRSA funds will fund the EHDI Program Manager position and a portion of the Program Coordinator position.

In the event of federal funding to support EHDI ending, the program would continue as it is required by State law and statute. Since its inception, the EHDI Program legislation is an unfunded mandate with no State General Funds designated to supporting the work. Given the ongoing current budget crisis in the State of Alaska due to the decline of oil prices, it is not realistic at this time to request or expect any State General Funds to support the Alaska EHDI program from the legislature or executive branch. Without HRSA funding, the State would need to divert funds from other public health projects and consider other revenue sources to help support the program, including state general fund dollars and the Title V Block Grant.

The aims of this grant are designed to support, enhance and develop strategies to increase timely hearing screening and follow-up at all stages of the EHDI process. Through accurate data, stakeholder input, small tests of change, thoughtful implementation, and statewide dissemination, it is believed that systems developed and improved through this process will be sustainable. Products and practices developed during this project, such as trainings and publication materials, will promote the ongoing best practice. These strategies will support families of children with hearing loss and assist providers in providing a timely standard of care.

## **WORK PLAN (in separate document) - *Attachment 1***

### **RESOLUTION OF CHALLENGES**

**Challenge #1:** Implementation of the EHDI Program throughout the State of Alaska requires overcoming the obstacles of vast geographic distances, severe climate, and sparse populations that may reside in isolated villages. Geography and access in remote regions of rural Alaska pose significant challenges to timely follow-up. Children born at remote regional hospitals often do not have access to audiology in their community or region, and most need to be flown to Anchorage for diagnostic follow-up.

**Possible Resolution:** Coordination with the statewide tribal health system is essential for problem solving issues surrounding access to follow-up in rural Alaska. If infants are discharged home to a remote community after a failed screen, travel needed to get to the clinic can have a significant impact on time to audiology follow-up. Many of these children are placed on a list to be seen at itinerant clinics where they are only re-screened, and comprehensive diagnostic assessment is further delayed. Pediatric audiologists are active participants on the EHDI Advisory Committee and essential partners for small tests of change. Two QI projects showed promise in mitigating this challenge. The EHDI Program, in partnership with ANMC, encouraged them to re-implement a previously successful strategy where a newborn that did not pass the initial hearing screening was scheduled for audiology diagnostics in Anchorage prior to the family being discharged to fly home to their community. This assessment before return home

strategy was recently spread to YKHC, and the initial results are promising. The second practice that was successful was the tele-audiology project with NSHC, which this regions uses efficiently and will be continue to be a valuable tool to address the challenge in their region. NSHC has shared lessons learned from their teleaudiology project; however, the infrastructure necessary to successfully reproduce this practice is not currently established in other areas of the state. Technical and equipment advances and workforce initiatives will continue to be explored to evaluate if teleaudiology can be spread successfully to other areas of the state.

**Challenge #2:** There continues to be a statewide shortage of health care professionals, including primary and specialty care providers, nurses, therapists and audiologists. A Community Health Aide Program, (CHAP) is often the primary care provider for community members in rural Alaskan villages. Their focus often is on meeting acute care needs in the community because of capacity and skill issues.

**Possible Resolution:** It is difficult for the EHDI Program to impact the number of health care providers who choose to practice in Alaska, though the program has had some success in this area in some regions of the state. The Program will continue to help support provider recruitment activities in collaboration with our health care partners. QI exercises related to the audiology referral and diagnosis process, and referral and enrollment into EI/ILP, will also drive improvements that will lead to more timely diagnosis and EI. It is more realistic for the EHDI Program to improve processes rather than increase the number of healthcare providers in some regions. Again, tele-audiology is also a strategy to address healthcare provider shortage and turnover and exploring the possibility of expanding the use in new regions will be a continued strategy.

**Challenge #3:** The Alaska EHDI system currently does not have a deaf navigator or guide program to offer services to families of diagnosed children by 9 months of age. The families of children who are diagnosed can reside anywhere in Alaska so providing guide services in remote communities could be challenging.

**Possible Resolution:** SSG, the family support grantee, will consult with FL3 to research evidence-based practices to build a new program. For families residing in remote communities, the program can consult with the local EI providers and regional audiologist to gather local ideas of an effective culturally informed means to offer support in that region. In some remote communities where children with hearing loss reside, but no adult guides have been identified, the program may offer virtual support or support in the hub community where the families receive medical and audiology care.

## EVALUATION AND TECHNICAL SUPPORT

The evaluation of the project will include a structured strategy of data collection for QI. Evaluation and monitoring will be ongoing throughout the project, utilizing the process, outcome, and impact measures identified in the evaluation plan table to determine success in meeting the overall program purpose, aims and objectives, as well as in implementing the individual project goals and objectives.

*Assessment of program-specific objectives*

The six Objectives (also called project goals) are those specified in the FOA. Alaska will utilize data from the EHDI-IS system to measure progress towards achieving Goals 1, 2 and 3. These goals pertain to improving timeliness of screening, diagnosis of hearing loss, and enrollment in EI. The EHDI-IS system includes information for every birth in the state regarding the birth and outpatient hearing screening results, referrals for diagnosis, and enrollment in EI (including date of enrollment). Age at screening, diagnosis and enrollment in EI can be calculated by using the date of birth field along with the date of screening, diagnosis and enrollment fields. Summary data can be produced in standard reports exported from the system, or data are exported as flat files and analyzed in Excel, depending on the need.

The EHDI-IS was designed by OZ Systems, located in Dallas, TX. OZ Systems designed and developed the EHDI-IS for Alaska in 2005. Through a five-year contract that began in 2017, OZ Systems currently provides server hosting, technical support, and use of their web-based surveillance system. EHDI Program staff use the system for data reporting and tracking infants throughout the National EHDI 1-3-6 process and tracking those infants requiring follow-up. OZ technical assistance provides guidance on creating queries to identify trends in lost to follow-up or referrals without diagnosis by physical location and identifiable data, as well as support for running other specialized searches for program data reporting. OZ has committed to partnering with the EHDI Program to produce an improved hospital report card that will reduce the staff time necessary to provide feedback to birth facilities.

Data on birth and outpatient hearing screening results and referrals for diagnosis for all infants born in Alaska are directly entered into the EHDI-IS system by staff at birthing hospitals, midwifery centers, and public health centers. The EHDI PC facilitates ongoing database trainings to address staff turnover and ensure consistency in data entry. OZ Systems provides manuals and technical assistance for data entry. An EI/ILP module was added to the database in December 2010. The module has the capacity to track when the referral was received by EI/ILP and the final disposition: enrolled in Part C, ineligible, declined, moved, etc.

In a new process which started in 2016, data from the EHDI-IS is linked weekly by the MCH Epidemiologist with a final birth file from the Section of HAVRS. The record linkage is conducted in SPSS and Microsoft Access. EHDI data are also integrated with newborn bloodspot data on a weekly basis. These processes allow for cleaning of data entry errors in dates of birth and identification of duplicate entries which improves data quality and allows for more complete contact information. As well, the linked birth certificate data provides additional and consistent demographic information on infants with hearing outcomes of interest (missed screens as well as hearing loss) that can be compared with infants without hearing loss to examine disparities in outcomes and identify target populations for further outreach. The MCH Epidemiologist who has over 10 years of experience analyzing vital records data and linking datasets is available to offer technical guidance on the data processes. Starting in 2019, the EHDI Program began a data match with the WCFH Alaska Birth Defects Registry Program. This match allows for the program to catch any diagnoses that may not have been entered into the EHDI-IS. It also allows the program to target outreach to providers that may not be entering timely data into the system.

One piece of demographic information from the birth certificate that will be useful in measuring progress among different cultural groups will be the maternal and paternal race from the birth certificate. Starting with 2013 births, Alaska transitioned to the 2003 version of the birth certificate, which allows for detailed information on multiple races to be indicated for both the mother and father. This information will enable the EHDI program to hone in on particular cultural groups as identified by race which may experience disparities in outcomes relevant to the EHDI program. In particular, the program will focus on infants with any Alaska Native race indicated on the birth certificate, as these infants have the benefit of access to a health care system that practices the PCMH model. At the same time however, many Alaska Native families live in areas of the state with a lack of services and providers. The Alaska Native population in Alaska will be the primary cultural group that the program will seek to improve outcomes among in work planned with the NSHC on increasing tele-audiology services to improve timely diagnosis in regions that do not have a resident audiologist.

Evaluation measures for Goals 1-4 will be calculated on a regular basis throughout the project period to ensure timely access to the information so that barriers can be quickly addressed and improvements capitalized on and effective strategies shared. For goal 2, the percent of infants born during the calendar month, four months prior to the current date, and who were diagnosed within 90 days of birth, will be calculated on a monthly basis. For example, the % of births during January 2017 who were referred and received a diagnosis within 90 days of birth will be calculated in April 2017. This four-month lag from date of birth will allow for all infants born in January to reach 90 days of age. The ongoing calculation of this measure will ensure that information on changes or delays can quickly inform QI efforts underway. By measuring this in a timely fashion, the Program will also be able to better determine the extent to which improvements in the measure may be attributed to project activities. Evaluation measures for goals 2 and 3 will be calculated every three months instead of monthly to account for smaller numbers in the denominators of all infants with hearing loss and all infants referred to EI.

Objectives 4 and 5 (Project Goal 4 and 5) speaks to developing and formalizing partnerships for family support and DHH adult peer guides. This funding opportunity will allow the EHDI program to build on current partnerships and agreements. WCFH has been funding SSG for parent navigation for a number of years and has a current agreement through 2022 supporting EHDI. WCFH also has a longstanding contractual relationship with CHD, the agency that houses the LEND program for Alaska. To assess this objective, we will annually review our agreements with SSG and LEND to ensure they are up-to-date and include all necessary evaluations components required as a part of the evaluation to HRSA. This will also ensure the partnerships continue to be mutually beneficial and are working to ensure that families of children who are DHH are receiving support. As part of the partnership, the Alaska EHDI program will work with SSG, FL3 and LEND on QI activities to improve experiences for families/parents/caregivers of newborns and infants who are DHH.

Finally, the Program identified Project goal 6 - to increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program by the end of the four-year project period. Increased knowledge of health professionals and service providers will be measured by an online survey of health providers, both those who participate in EHDI training activities, as well as those who don't, in order to have a comparison and evaluate the

effectiveness of the trainings. In addition, every EHDI outreach and educational activity will conduct a pre-post test of knowledge among participants, to measure the extent to which increased knowledge can be attributed to the project. This data will be kept in the Program Manager's records.

### *Quality Improvement (QI) activities*

The primary QI tool that will be utilized throughout the project is the PDSA cycle. WCFH has received training on and is most familiar with this tool. The EHDI Program is open to learning and utilizing new tools that may be a better fit for some QI priorities. The PDSA is a four step iterative process for creating and implementing change through ongoing monitoring and evaluation. In the *Plan* stage, programs identify and prioritize opportunities for improvements. They clearly define and describe the problem to be addressed by collecting as much information as possible. A cause and effect diagram may be used to identify possible causes of the problem, and potential solutions are developed. Finally, an action plan is created. In the *Do* stage, programs implement the action plan in a small, controlled environment so that they can examine closely how the change is working by collecting data. In the *Study* stage, these data are reviewed and evaluated, and lessons learned are documented. In the *Act* stage, participants reflect on what was learned and may standardize the improvements by implementing them more widely, adjust the process, or abandon the tested process to try something else. The EHDI-IS will be queried to provide data to inform the plan stage of QI activities to address goals 1, 2 and 3.

Another source of data for QI processes will be the CHD survey of families of infants with confirmed permanent hearing loss and lost to follow up. These interviews will help the program to better understand barriers to receiving a diagnosis, early enrollment or reasons for non-enrollment in EI or family support services. Interviewing families will provide richer and more detailed qualitative and quantitative data on reasons for not receiving a diagnosis, enrolling in EI or family support versus data available from the EI program. Additionally, some families of children with hearing loss may never have been referred to EI, so their reasons for non-enrollment would not be captured or known to EI. Because the number of infants diagnosed with hearing loss in Alaska every year is relatively small (around 20), one-on-one interviews with each family will be manageable and is preferable to an online or paper survey which is likely to have a lower response rate. In addition, it may be easier to collect qualitative data and anecdotes from families through in person interviews compared to a survey where it would not be possible to prompt or follow-up on certain comments provided. Focus groups are also unlikely to be useful due to the number of families in the target population and the small likelihood that multiple target families live in the same city or village. The parent interviews will be conducted statewide by parents of DHH and will represent various cultures of Alaskans affected by a family member with hearing loss, including Alaska Native people.

Throughout the project, we will monitor the cost of implementing improvements to ensure project activities are efficient. Costs of various options will be compared and discussed with stakeholders and among the QI team.

### *Potential obstacles to evaluation*

Alaska is a small state in regards to population. Small numbers are a consistent obstacle to evaluating many public health programs in Alaska and make it difficult to detect significant trends or changes. To resolve this as much as possible, we will combine years or months, depending on the measure, to increase the size of the denominator population.

Another obstacle related to the small population is that EHDI and other public health programs often partner with the same entity multiple times, including on QI initiatives. Given that Alaska is a fee-for-service state, it can be difficult to engage providers in the private sector to do additional work as it costs them money. This is less challenging in the military and tribal health systems where providers are salary and not productivity based. The EHDI Program has the benefit of having already established partnerships with the entities listed in the work plan and evaluation plans. This includes already established contracts and MOUs that will just be modified to include the work planned for this project.

## PERFORMANCE EVALUATION MEASURES

**AIM/IMPACT 1: AIM/IMPACT 1: To maintain 95 percent screening rate the number of infants that completed a newborn hearing screen no later than 1 month of age through March 31, 2024.**

| <b>Objective/Outcome 1.1: By March 2023, at least 65% of newborns without a successful newborn screen will have a screen/rescreen, or an audiology appointment within the first month of age.</b> |   |                                   |  |  |
|---|---|-----------------------------------|--|--|
| <b>Evaluation Measure</b>   | <b>Purpose and Measure Type</b>   | <b>Data source</b>                | <b>Staff responsible</b>                 | <b>Time frame</b>                                      |
| The proportion of newborns who received a hearing screening within their first 30 days of life.   | To measure the proportion/number of newborns that have been screened within 30 days (Outcome) | EHDI-Information System (EHDI-IS) | EHDI Program Manager (PM)                | Annually, in April                                     |
| The number of infants who received a hearing screening during a 3 month time period   | Monitor progress towards achieving program objective (Process)                                | EHDI-IS                           | EHDI PM                                  | Every 3 months, ongoing                                |
| The number of letters sent to families that have no record of a hearing screening   | Monitor progress towards achieving program objective (Process)                                | EHDI-IS                           | EHDI PM                                  | November 2020  |
| The proportion of two month old infants who were identified and referred to audiology after their 30 day newborn hearing screen   | Measure the extent to which program objective has been met (Outcome)                          | EHDI IS                           | EHDI PM<br>EHDI Program Coordinator (PC) | At baseline and at the end of every quarterly, ongoing |

| <b>AIM/IMPACT 2 To increase to 38%, the number of infants that have completed a diagnostic hearing evaluation no later than 3 months of age.</b>                          |   |   |                    |   |
|---|---|---|--------------------|---|
| <b>Objective/Outcome 2.1: By March 2024, 38% of all newborns who did not pass their newborn hearing screen will have an audiology appointment by three months of age.</b> |   |   |                    |   |
| Evaluation Measure  | Purpose and Measure Type  | Data source   | Staff responsible  | Time frame                              |
| The number of newborns and infants who were referred for a diagnostic assessment within the first three months of life.   | Measure the extent to which program objective has been met (Outcome)            | EHDI IS   | EHDI PM<br>EHDI PC | At baseline and every 3 months, ongoing |
| The number of infants with hearing loss who were diagnosed by three months  | Measure the extent to which program objective has been met (Outcome)            | EHDI IS<br>Early Intervention/Infant Learning Program (EI/ILP) data | EHDI PM<br>EHDI PC | At baseline and every 3 months, ongoing |
| The number of faxes sent to healthcare provider for an infant who were referred to an audiologist and who did not have an evaluation in 90 days                           | Measure the EHDI contact with PCPs to encourage audiology evaluations (Process) | EHDI IS   | EHDI PM<br>EHDI PC | Ongoing                                 |
| <b>AIM/IMPACT 3: To increase to 58% the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.</b>                        |   |   |                    |   |
| <b>Objective/Outcome 3.1: To identify the three most common barriers to EI/ILP enrollment for DHH infants and their families by March 31st 2024.</b>                      |   |   |                    |   |
| Evaluation Measure  | Purpose and Measure Type  | Data source   | Staff responsible  | Time frame                              |
| # of newborns and infants with hearing loss who are enrolled in EI services by 6 months   | Measure the extent to which program objective has been met (Impact)             | EHDI IS<br>EI/ILP data  | EHDI PM<br>EHDI PC | At baseline and every 3 months, ongoing |
| # of newborns and infants with hearing loss who were not enrolled in EI services by 6 months  | Measure the extent to which program objective has been met (Impact)             | EHDI IS<br>EI/ILP data  | EHDI PM<br>EHDI PC | At baseline and every 3 months, ongoing |
| # of families of infants  | Monitor progress  | Program   | EHDI PM            | August-September                        |

| with hearing loss surveyed about reasons for non-enrollment   | towards achieving program objective (Process)  | records                | EI staff          | 2017                                      |
|---|--|------------------------|-------------------|---|
| Financial cost (if any) of implementing improvements identified through PDSA  | Monitor efficiency of project activities (Process)   | EHDI budget documents  | EHDI PM           | ongoing                                   |
| <b>AIM/IMPACT 4: To increase by 20 percent from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age.</b>                 |  |                        |                   |   |
| <b>Objective/Outcome 4.1: All parents with a DHH diagnosed child will be offered Stone Soup Group (SSG) parent navigation services by March 2024.</b>                               |  |                        |                   |   |
| Evaluation Measure  | Purpose and Measure Type   | Data source            | Staff responsible | Time frame                                |
| Current, up-to-date contract in place with Stone Soup Group   | Measure the extent to which program objective has been met (Impact)  | EHDI records           | EHDI PM           | Annually                                  |
| % of parents of children diagnosed with hearing loss in the past 6 months offered support through SSG parent navigation services  | Monitor progress towards achieving program objective (Outcome)   | SSG records<br>EHDI IS | EHDI PM<br>SSG    | At baseline and every 6 months thereafter |
| Ratio in the % of parents of children with hearing loss offered family support through SSG parent navigation services at the end of the project period compared to baseline         | Measure the extent to which increased use of SSG parent navigation services can be attributed to the project (Outcome) | SSG records<br>EHDI IS | EHDI PM<br>SSG    | At baseline and March 2016                |
| Average # of days between child's diagnosis of hearing loss and family contact by SSG parent navigator  | Monitor the effectiveness of strategies to address barriers to timely offering of family support services (Outcome)    | SSG records<br>EHDI IS | EHDI PM<br>SSG    | At baseline and every 6 months thereafter |
| <b>Objective/Outcome 4.2: By March 31, 2024, , one Parent Survey will be conducted to gather information from the families of children who were referred for follow up on their</b> |  |                        |                   |   |

| <b>newborn hearing screening and did not receive the recommended follow up.</b>   |  |  |                               |                   |
|---|--|--|-------------------------------|-------------------|
| <b>Evaluation Measure</b>   | <b>Purpose and Measure Type</b>                                      | <b>Data source</b>                         | <b>Staff responsible</b>      | <b>Time frame</b> |
| Current, up-to-date contract with LEND program in place   | Measure the extent to which program objective has been met (Impact)  | EHDI records                               | EHDI PM                       | Annually          |
| The number and proportion of families who responded to the survey   | Monitor progress towards achieving program objective (Process)       | CHD-LEND RECORDS                           | LEND Staff                    | Annually          |
| The LEND-CHD staff report will be delivered   | Monitor progress towards achieving program objective (Outcome)       | LEND program records                       | LEND Staff                    | Annually          |
| Final report from LEND to the EHDI Advisory Committee   | Monitor progress towards achieving program objective (Outcome)       | LEND program records/ EHDI meeting minutes | LEND Staff Advisory Committee | Annually          |
| <b>AIM/IMPACT 5: To increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.</b>  |  |  |                               |                   |
| <b>Objective/Outcome 5.1: 80% of Families with a diagnosed DHOH child will be offered opportunities to enroll in DHH adult to family support services by no later than 9 months of age by March 2024.</b> |  |  |                               |                   |
| <b>Evaluation Measure</b>   | <b>Purpose</b>   | <b>Data source</b>                         | <b>Staff responsible</b>      | <b>Time frame</b> |
| Maintain a current, up-to-date annual grant with the Stone Soup Group (SSG).  | Measure the extent to which program objective has been met (Impact)  | EHDI records                               | EHDI PM                       | Annually          |
| DHOH guide training materials chosen and obtained   | Measure the extent to which program objective has been met (Outcome) | SSG records                                | SSG Staff                     | June 2021         |

|   |  |                        |                |   |
|---|--|------------------------|----------------|---|
| # of DHOH Guides trained by SSG   | Measure the extent to which program objective has been met (Outcome)   | SSG records            | SSG Staff      | August 2021                               |
| % of parents of children diagnosed with hearing loss in the past 6 months offered support through SSG parent navigation services                                    | Monitor progress towards achieving program objective (Outcome)   | SSG records<br>EHDI IS | EHDI PM<br>SSG | At baseline and every 6 months thereafter |
| Number of parents of children with hearing loss offered family support through SSG parent navigation services at the end of the project period compared to baseline | Measure the extent to which increased use of SSG parent navigation services can be attributed to the project (Outcome) | SSG records<br>EHDI IS | EHDI PM<br>SSG | At baseline and March 2016                |
| Average # of days between child's diagnosis of hearing loss and family contact by SSG parent navigator  | Monitor the effectiveness of strategies to address barriers to timely offering of family support services (Outcome)    | SSG records<br>EHDI IS | EHDI PM<br>SSG | At baseline and every 6 months thereafter |

**AIM/IMPACT 6: To increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.**

**Objective/Outcome 6.1: Three trainings will be offered to health professionals and service providers trained on key aspects of the EHDI Program by 3/31/2024.**

| Evaluation Measure   | Purpose  | Data source                                | Staff responsible | Time frame                       |
|--|--|--|-------------------|----------------------------------|
| The proportion of healthcare professionals surveyed reporting knowledge of the “1,3,6 National EHDI goals” | Measure the extent to which program objective has been met (Outcome) | Online survey of health professional staff | EHDI PM           | September 2021 and December 2024 |
| The number of trainings offered to healthcare professionals and service providers on the EHDI Program.     | Monitor progress towards providing educational opportunities for     | EHDI records                               | EHDI PM           | March 2024                       |

|  | providers<br>(Process)   |                      |   |         |
|--|--|----------------------|---|---------|
| The proportion of health professional staff who participated in outreach and educational activities who increase their knowledge of key aspects of the EHDI Programs | Measure the extent to which increased knowledge can be attributed to the project (Outcome) | Pre-post test        | EHDI PM   | ongoing |
| Presentation   | Measure the extent to which program objective has been met (Outcome)                       | EHDI Program Records | EHDI PM<br>LEND Staff<br>Chapter Champion<br>Parent Leaders | ongoing |

## ORGANIZATIONAL INFORMATION

Alaska's EHDI Program is located within the Perinatal & Early Childhood Health Unit (PECHU) of the Section of Women's, Children's, and Family Health (WCFH). The mission of WCFH is to promote optimum health outcomes for Alaskan women, children, teens, and their families. Alaska's Title V Maternal Child Health (MCH) and CYSHCN programs are also located within the Section. The Title V Director serves as Section Chief for WCFH, and the CYSHCN Director serves as the Unit Manager for the PECHU.

Other programs located within the PECHU include the Maternal, Infant, & Early Childhood Home Visiting (MIECHV) program, Early Childhood Comprehensive Systems, CYSHCN, newborn bloodspot and pulse oximetry screening, pediatric specialty clinics, and other perinatal health programs which support Title V efforts around infant safe sleep, breastfeeding, and decreasing substance use during pregnancy. The PECHU Manager provides supervisory support including consultation and guidance to the EHDI Program staff and seeks to align the EHDI program with other CYSHCN efforts. The EHDI Program has a long history of contributing to Title V Block Grant efforts, including grant writing and reporting. Other programs located within the Section include Women's Health, School Age and Adolescent Health, and MCH Epi Unit.

The Section is located with the Division of Public Health (DPH) which resides in the Department of Health & Social Services (DHSS) 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".

In 2019, the Division began pursuing plans to become an accredited public health agency. Many WCFH staff members have been part of workgroups to lead this effort. Through a prior strategic planning process in 2015, the Division identified six winnable battles in which to focus public health efforts across the state. They were: decreasing tobacco and nicotine use, decreasing colorectal and cervical cancer, increasing access to health care, improving child and adolescent health, decreasing infectious disease, and preventing poisoning and overdose. Alaska's EHDI

program fits nicely with the winnable battles of increasing access to health care and improving child and adolescent health. In 2019, the new leadership of DPH began a new strategic planning process to determine priority values and focus areas for the upcoming years. The Section Chief has been in a leadership role related to the formation of the new DPH Strategic Plan.

The EHDI Program is managed by a Public Health Specialist (PHS) II who serves as the EHDI Program Manager with support from the Program Coordinator (PC) I. The PC 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 PC runs reports and exports follow-up letters and faxes to providers and facilities from the database. The PC has also been a part of QI efforts since the NICHQ Learning Collaborative in 2011 and has worked on PDSA cycles for the EHDI program. WCFH, along with the DPH as a whole, has put an emphasis in recent years on the importance of continuous quality improvement (CQI). All DPH staff have received training on CQI, and the Division has an active cross-sectional QI Team whose mission is to align and strategize work within DPH to be more efficient and effective by promoting and supporting QI projects. WCFH programs have been actively participating in ongoing CQI efforts in programs such as EHDI, newborn bloodspot screening, Title V, MIECHV, CYSHCN, among many others. The PECHU Unit Manager also has experience leading CQI efforts in the MIECHV program. In the past, the EHDI program has had success using PDSA cycles to trial certified letters to decrease LTFU, increasing PCP communication with families at risk to LTFU, and also piloting the use of email notification in a tribal health hospital to increase timely data entry. This was done in collaboration with an EHDI-NTRC QI contractor.

Another unit within WCFH is the MCH-Epi Unit which collects and manages 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. The MCH-Epi Unit also facilitates Alaska's Maternal Child Death Review (MCDR) committee and Alaska's child abuse and maltreatment surveillance system (ALCANLink). The MCH-Epi Unit has staff members with extensive education, training, and experience with data analysis and other program evaluation. There are currently two staff members with PhDs in the Unit. The MCH-Epi Unit has been and will continue to be available to support the EHDI program through data analysis and program evaluation support. In 2017, WCFH precipitated in a technical assistance opportunity from the Association of Maternal Child Health Programs (AMCHP) to host two Harvard University/CDC evaluation interns with the EHDI program. This opportunity also allowed the EHDI Program Manager, Program Coordinator and the MCH-Epi Unit Manager to receive in-person technical assistance and additional training from CDC on program evaluation. The Harvard practicum evaluation centered on evaluating Alaska's efforts to increase reduce the loss to follow up and loss to documentation rates. The evaluation recommended the program conduct a parent survey to understand the barriers to families in Alaska receiving the recommended follow up by the 1,3,6 time goals. This recommendation was put into action in 2018-2019 thought the CHD Parent Survey.

There is also legislative support and requirements related to the EHDI program. Legislation mandating newborn hearing screening was passed in May 2006 and was enacted on January 1, 2008. Statutes and Regulations were written and implemented at that time. There are provisions

in the mandate that include regulations around screening, reporting, and connections to audiology and EI. Newborn hearing screeners and audiologists report to the State by entering data directly into the OZ database. In 2017, the EHDI Program also implemented a HAVRS matching tool which has better integrated birth certificate data into the newborn bloodspot and hearing screening data in the OZ database. Data is downloaded into the database on a weekly basis and indicates which facilities are behind schedule in entering hearing screening data, as well as data on OOH births.

Data from the OZ database, along with data sources in the MCH Epidemiology Unit, are used to determine target populations for education and change strategies. For example, OZ data will be reviewed to determine the impact of the current process measures to better understand the barriers to diagnosis, and the extent to which families are utilizing EI. The EHDI Program staff have been successful in utilizing and understanding the functions of the OZ database and will continue to utilize the EHDI-IS data when conducting PDSA cycles mentioned in the work plan. The EHDI program has a strong history of using data to drive program efforts and interventions. For example, in a past funding cycle, as the majority of lost to follow-up were occurring with tribal health facilities, military hospitals, and OOH births, the Program focused work plan efforts specifically around these populations, successfully reducing loss to follow documentation from military facilities.

WCFH continues to look for ways to become more culturally informed and to ensure services are meeting the needs of the population. The newborn hearing screening brochure was modified for OOH births and was reviewed by a group of parents, as well as the state's Public Information Team, for cultural and linguistic competency and health literacy. WCFH has also received technical assistance on cultural competency for staff in 2018 through technical assistance from Title V. The EHDI Program has a strong history of collaboration with partners to ensure efforts are culturally informed and relevant to the populations. This includes partnerships with tribal health and also working with the midwiferies. The EHDI Program Manager has also made strides in collaborating more with the DHH community. She regularly participates in community events to strengthen that relationship. This also led to more parent of deaf children participation on the EHDI Advisory Committee. In 2019, WCFH staff all received training sessions on making documents and websites ADA accessible.

The EHDI Program also has an advantage in that there is a strong, participatory, and collaborative EHDI Advisory Committee with long-standing and dedicated members. Family participation has historically been strong with the Committee and has included active participation from birthing facilities, primary care providers, audiologists, parent navigators, tribal health, military representatives, among many others. Both family and provider engagement have been strong.

The EHDI Program already has existing working relationships with State of Alaska EI staff and grantees, the Governor's Council on Disabilities and Special Education, Head Start programs, Stone Soup Group, the Alaska LEND program, among many others. This includes existing grants, contracts, and memorandums of agreement with LEND, Stone Soup Group, and NSHC Corporation.

The EHDI Program Manager started in the position in February 2016 and comes to the role from the Senior & Disabilities Services. She has a Bachelor's in Social Work and experience with

waivers for children with complex medical conditions and has a history of working with health care providers, telehealth providers, early interventionists, and care coordinators. She has continuing education in quality improvement, evaluation, research, and adult education. As a child of a deaf adult, she has brought relevant life experience to her work in the Program. She participated in the project to begin teleaudiology in the state and co-presented an instructional and break out session on teleaudiology at the 2019 National EHDI Meeting. She collaborated with CHD-LEND on development of the 2019 parent survey. Her commitment to parent learning opportunities was evidenced by the fact that she insisted that the parents of DHH children be hired and trained survey takers for the family survey project though recruiting and training the parents.

The Program Coordinator is a deaf adult trained guide, as well as long-standing member of the EHDI team who also brings in his experience as a parent of a CSHCN. He is also the WCFH Family Engagement Lead, the State of Alaska AMCHP Family Advocate, a past LEND Family Advisory Council (LFAC) member, a past LEND Host Family, and manages the SSG family support grant. He has extensive experience with the OZ database and working with families, health care providers and audiologists. He also won the Oticon Award in 2017.

While not funded by the HRSA grant, the EHDI Program also had a Research Analyst I and Office Assistant II that provide more research, data and administrative support to the program. (Attachment 5 organizational chart).

The program is also funded by the EHDI CDC grant which funds the EHDI-IS development and expansion. This system provided the ability to track children from birth through EI enrollment. The system also can be used to routinely assess and improve the unique needs of target populations of the communities serve to identify if QI projects are achieving the desired outcomes.

The program has used data from the EHDI-IS to exchange and research populations that may need outreach then track the progress of these efforts. A recent example of data matching and exchange was the data sharing between ABDR and EHDI which identified children in birth year 2017 and 2018 that were not documented in the EHDI-IS as diagnosed. This data exchange is planned to continue twice a year with the MCH-Epi providing technical assistance to the EHDI Research Analyst I.

The program has plans to collaborate with FL3, NTRC to revise and increase EHDI publications in a culturally informed manner. Past publications include the EHDI brochure, audiology practice guidelines, the Governor's report on the EHDI program, EHDI 2019 Program Evaluation and Parent Survey. The EHDI program has also been revising the program website to ensure accessible, culturally competent, and relevant material. The program is exploring submitting an abstract with CHD-LEND on the parent suvey for the EHDI conference.

The EHDI Program requires regular reporting on the financial status of contracted agencies. WCFH and the EHDI program regularly track expenditures using the DPH prescribed financial tracking a management processes. The State of Alaska also has a financial management system and personnel who assist in providing support to programs in ensuring proper tracking of federal funds, completing federal financial reports, create summary reports, etc.

