Grant Number:	HRSA-20-047
Project Title:	Early Hearing Detection and Intervention Program
Organization Name:	Idaho Department of Health and Welfare
Mailing Address:	450 W. State St., 5 <sup>th</sup> Floor
	Boise, ID 83720
Primary Contact:	Brian Shakespeare
-	Early Hearing Detection and Intervention (EHDI) Program Coordinator
	208-334-0983
	Brian.Shakespeare@dhw.idaho.gov

# ABSTRACT

Idaho Early Hearing Detection and Intervention (EHDI) works vigorously to ensure Idaho meets the Joint Committee on Infant Hearing (JCIH) 1-3-6 goals for Universal Newborn Hearing Screening (UNHS). Program activities ensure all newborns are: 1) screened for hearing loss prior to discharge from all birthing centers, or at least by one month of age; 2) receive appropriate pediatric audiology testing by three months of age; and 3) are tracked to ensure delivery of follow-up early intervention (EI) services by six months of age. These actions ensure all Idaho infants with hearing loss attain developmental progress equal to their normal hearing peers. The focus of Idaho EHDI is to: 1) maintain or increase the current rate of Newborn Hearing Screening (NHS) to 98%; 2) increase the number of infants who receive timely diagnosis by 10% from baseline; and 3) increase by 15% from baseline the number of newborns and infants identified to be deaf or hard of hearing (D/HH) who are enrolled in EI services by six months of age. Baseline data will be based upon the 2017 Centers for Disease Control Early Hearing Detection and Intervention Hearing Screening and Follow-up Survey. Currently, 56% of Idaho infants receive timely hearing loss diagnosis. The rate of infants identified with hearing loss and enrolled in EI services by six months of age is 53%. Current successful interagency collaborations will be continued, and Idaho EHDI will seek to develop partnerships supported by a memorandum of understanding with established family-based support organizations and/or programs focused on families/parents/caregivers of newborns and infants who are D/HH. Thorough program evaluation will be completed annually by the Idaho EHDI Advisory Committee.

### **PROJECT NARRATIVE**

### **Introduction**

Universal Newborn Hearing Screening in Idaho is a collaborative and voluntary effort to achieve the JCIH goals of screening all infants by one month of age, diagnose hearing loss by three months of age, and ensure all infants with hearing loss are enrolled in EI services by six months of age. Idaho EHDI's goal is to increase the number of infants who receive timely diagnosis from 56% to 66%. Through rigorous data collection and analysis, Idaho EHDI has identified the point in the NHS process where newborns become Loss to Follow-up (LTF). Strategic Plan, Do Study Act (PDSA) cycles and Quality Improvement in pilot birthing facilities reduced LTF and increased timely diagnosis of hearing loss. These initiatives have recently been spread throughout the state and have increased the percentage of timely diagnosis statewide. Over the next four years, infants enrolled in EI services will increase from 61% to 76% through the continued partnership of Idaho EHDI, Idaho Educational Services for the Deaf and the Blind (IESDB), and the state Part C program. Efforts will be initiated to strengthen relationships among parents, medical agencies, and intervention services. Idaho EHDI has created a learning community consisting of community care coordinators, primary care providers (PCP), and parents of children with hearing loss to increase healthcare providers' knowledge of hearing loss and Idaho EHDI processes and procedures. In 2017, these efforts resulted in an increase in the number of infants who received timely diagnosis from 56% to 63.8% and a slight increase in the number of infants enrolled in EI services (from 61% to 61.7%).

The Idaho Department of Health and Welfare (DHW), Division of Family and Community Services (FACS), Infant Toddler Program (ITP) has oversight of and is the lead agency for Idaho EHDI project. Idaho EHDI partners with Idaho's birthing facilities, ITP regional offices, Early Head Start (EHS) programs, IESDB, and the Idaho chapter of Hands and Voices (H&V). Idaho EHDI will continue to construct partnerships supported by memorandums of understanding with other established family-based support organizations or programs focused on families/parents/caregivers of newborns and infants who are D/HH.

Universal Newborn Hearing Screening has been endorsed by the Idaho Hospital Association (IHA) as "standard of care" since 2002. Voluntary hospital participation and support for NHS is extraordinarily high. The continuing level of hospital participation and support for hearing screening is reflected in the 2017 rate of 98%. Thirteen hospitals received financial assistance to purchase and maintain Automated Auditory Brainstem Response (AABR) screening equipment since 2010. Idaho EHDI bought ten Otoacoustic Emission (OAE) screeners for the purpose of loaning them to hospitals and midwives. Currently, four are on loan in low-birth-count hospitals and three are placed in midwife clinics. Each of the 31 Idaho birthing hospitals voluntarily submits hearing screening data bi-monthly to Idaho EHDI. The EHDI-IS is utilized by all 31 hospitals for data reporting purposes. On average, Idaho EHDI has identified 68 infants with hearing loss per year in the last ten years.

The Idaho EHDI-IS is used to track and document the status of every child identified with hearing loss through the screening program. This system identifies infants who need follow-up and those who are at risk of LTF/Loss to Documentation (LTD). A well-planned, integrated system is essential for identifying system gaps in service provision, planning for process improvements, and increasing the capacity of the program to accurately collect and analyze data. Centers for Disease Control and Prevention funding is utilized for project activities designed to increase the timeliness with which the state receives NHS data, allowing for follow-up and tracking activities. This is accomplished through upgrading the EHDI-IS statewide and the ability to access it through a web-based system. All thirty-one hospitals use the web-based EHDI-IS and upload their screening data, making it possible for the data to be analyzed in near-real time.

All hospitals use the Idaho EHDI Screening Results Form (SRF) to report infants who refer on their NHS and/or have risk indicators for hearing loss. Performance reports are generated for each birthing facility and measured against the JCIH benchmarks. This gives the facility timely feedback on their Key Performance Indicators (KPI). Performance reports to hospitals include

suggestions for improving metrics in which they are under-achieving. Audiology consultants provide regular outreach to NHS programs, including in-person training and technical support.

The Idaho EHDI program has loan agreements with five licensed midwife practices. These centers were provided technical support, equipment, and training necessary to initiate NHS programs. Recently, due to logistical challenges, two midwiferies terminated their NHS programs and have begun to refer families of newborns to Idaho EHDI. Once Idaho EHDI is contacted by the family, they are referred to their regional ITP office, which provides in-home hearing screenings at no charge to the family. The remaining five facilities report screening results through the Idaho EHDI-IS web application. In addition, all five clinics utilize the Idaho EHDI SRF to submit individually identifiable information on babies that refer on their screenings. Between 2015-2018, six children born out-of-hospital were diagnosed with hearing loss, demonstrating the significance of these partnerships.

Idaho EHDI continues to promote the availability of UNHS in all promotional materials. Parents can connect with these services either directly through the Idaho EHDI office or through Idaho 2-1-1 CareLine, a free, statewide community information and referral service.

Idaho EHDI's partnership with ITP regional offices includes providing information and education on screening training techniques and best practice guidelines. The Infant Toddler Program is responsible for maintaining a data collection system that captures EI enrollment and service data required for management and reporting. An electronic linkage between the ITP database and Idaho EHDI-IS has been established where records are automatically merged to facilitate information sharing, thus increasing the ability and effectiveness to provide timely EI services. Idaho EHDI can access the ITP database to review enrollment status of children referred due to hearing loss.

Idaho has seven EHS programs, including two Tribal programs, serving approximately 1,535 children ages birth to three. The program promotes healthy births and provides support for infants and toddlers of low-income families. Early Head Start programs are mandated to screen children for health and developmental issues, including hearing, within thirty days of enrollment. Over the last several years Idaho EHDI has provided the EHS programs with educational outreach regarding the importance of hearing screenings and follow-up. Beginning in 2013, with support from Idaho EHDI, four of the EHS programs were able to attend hearing screening training and are now participating in the National Early Childhood Hearing Outreach (ECHO) initiative. Three EHS programs received financial assistance from Idaho EHDI in order to purchase hearing screening equipment.

In 2017, twenty-six Idaho audiologists were sponsored by Idaho EHDI to attend a pediatric audiology training offered by the National Center for Hearing Assessment and Management (NCHAM). In 2018 Idaho EHDI increased the number of sponsored audiologists to 50. Idaho EHDI continues to provide scholarships for Idaho audiologists to attend in-state pediatric audiology trainings.

Guide by Your Side (GBYS), a nationally recognized parent support program, has launched a chapter in Idaho with parent guides throughout the state. Idaho EHDI works closely with GBYS,

and once a diagnosed hearing loss is made, the referral is sent to the GBYS Coordinator who relays it to the parent guide in the appropriate region of the state. A coordinated effort between Idaho EHDI, GBYS, ITP, and IESDB ensures every child and family has the opportunity to succeed as they navigate the hearing loss journey.

In addition, The CARE Project (TCP) has successfully been brought to Idaho in 2018 and 2019. The CARE Project "is a nonprofit organization dedicated to bringing hope to families who have children and/or adults with hearing challenges through counseling experiences aimed at the processing of the emotional stages of grief. The CARE Project is also a tool for teaching professionals and pre-professionals about the importance of active listening with their clients/patients and validating their emotional state." At the inaugural CARE Project retreat in 2018, ten families attended, with seven families attending in 2019.

Idaho EHDI comprises a passionate and dedicated staff and enjoys strong support from its stakeholders. The Idaho EHDI AC has members throughout the state who focus on target populations with varying needs. The committee works to support and ensure that the goals of Idaho EHDI are met through strategic planning, critical feedback, and coordination of services.

### Needs Assessment

Identifying why infants are LTF/LTD is the principal task in formulating corrective action through PDSA processes and QIs. The needs assessment assumes that LTF/LTD occurs at specific points in the NHS process. Idaho is a rural state with regional pockets of population that do not have equal access to pediatric audiology services. Inclement weather limits access to services several months of the year across the state. Idaho has significant uninsured/underinsured populations of infants, as well as large numbers of infants at or below the national poverty level. Audiology services are not required benefits in the Affordable Care Act, thus coverage for these services is not expected to improve.

The state of Idaho comprises 44 counties, most of which are rural and/or remote. The Idaho Department of Health and Welfare has categorized the 44 counties into seven regions. United States Census estimates from 2017 indicate a total population of 1,754,208. Sixty-Two percent of the state's population, that is, 1,099,370 residents, reside within five cities or metro areas (Boise Metro area, Coeur d'Alene, Idaho Falls, Pocatello, Lewiston) representing four of the seven regions. Forty-four percent of all Idaho children under the age of five live within these five metro areas. These five distinct population centers consist of a combined land area of 299.58 square miles. The remaining 654,838 Idaho residents are dispersed throughout the remaining 82,343.54 square miles of the state. Thirty-nine percent of the total state population lives within the Boise Metro Area (consisting of the cities of Boise, Meridian, Eagle, Star, Kuna, Nampa, and Caldwell), representing two of the seven regions (Attachment 7.1).

The population density illustrates the extremely rural nature of Idaho. Severe weather conditions and limited road access in the majority of the state affect travel a number of months each year. This is a difficulty with which medical professionals, support services, and families seeking care must cope. Most trainings and hospital/ birthing center outreach visits must be limited to seasonally favorable months in which driving dangers are limited. Air travel is frequently the

most efficient way to reach outlying areas, especially in winter months.

Northern Idaho comprises two regions/ten counties totaling 25% of the total land area in Idaho, with access to one pediatric audiologist within state borders. For many families, the closest pediatric audiology clinic is located more than 150 miles away in a bordering state. The residents of these counties total 20% of the total Idaho population (349,876 of 1,754,208) as of the 2017 US Census Estimates. According to Idaho Vital Records (VR) Health Statistics, in 2017, 16.5% of all births in the state (3,591 of 21,826 reported births) occurred in these two regions. The lack of services in this area prevents a significant portion of Idaho's population from receiving proper care that is accessible in other regions of the state. Also, the size of the individual hospitals and birth numbers vary widely, primarily due to the rural nature of the state and unequal distribution of Idaho residents, which impacts training and follow-up availability. Most of the smaller Idaho hospitals are in rural areas, with 18 of the 32 hospitals being critical access hospitals (Attachment 7.2).

The Kids Count Data Center reported in 2016 that 21,452 children in Idaho were uninsured, and the 2017 estimate shows 20.1% of Idaho children live below the poverty level. When compared with other states, Idaho ranks 26<sup>th</sup> in the country with respect to residents living at or below the national poverty level. According to America's Uninsured Children, a 2006 study completed by the Children's Health Campaign, uninsured children are three times as likely to go without any type of health care for a year or more. This is a contributing factor to Idaho's LTF rate. Idaho EHDI connects these children to ITP, which aids parents in finding diagnostic testing services and access to EI services. Idaho EHDI has a network of programs that provides loaner hearing aids to children in need. Parents in poverty often lack the knowledge of how to find these services on their own. Idaho EHDI provides a vital connection between these parents and the services crucial for their children to thrive.

Idaho EHDI collaborates with the Idaho Head Start Program, which serves disadvantaged children from birth to age five. Within the Head Start program are several other programs including EHS which focuses on children ages birth to three years old, and Migrant Head Start (MHS) which specializes in meeting the needs of children of migrant seasonal workers who relocate throughout the year dependent upon employment availability. In 2017, Idaho Head Start programs enrolled 5,154 children, 30% (1,535) of which were under three years old. Idaho EHDI plans to assist MHS in the expansion of their screening program in order to serve a population that does not fit into the traditional medical home model.

In 2017, 605 Idaho newborns referred on their NHS, with 171 LTF, placing the LTF rate at 28%. One hundred thirty families were contacted but unresponsive regarding follow-up testing and 41 are classified as unable to contact. This has been addressed by sending families a certified letter requiring a signature to confirm delivery if the family has not received follow-up testing, or our Parent Outreach Coordinator (POC) is unable to establish contact via telephone. As of July 5, 2019, Idaho EHDI records confirm that 70% of certified letters are delivered. Idaho EHDI will adopt this practice as standard operating procedure.

In 2017, five Idaho licensed midwife practices participated in UNHS by utilizing OAE screening

equipment loaned from Idaho EHDI. Eighty-two percent of newborns were screened within the first month of birth with a refer rate of 9%. This is still within an acceptable OAE refer rate. Idaho EHDI continues to reach out to midwives and encourage screening for all children.

In 2017, 22,356 births were reported to Idaho EHDI by hospitals and midwives, whereas VR reported 21,826 births. The variance (530) demonstrates the importance of data sharing. Many infants diagnosed with hearing loss are referred to EI services for disabilities other than hearing loss. Hearing loss diagnosed after initial intake is rarely reported to Idaho EHDI. Therefore, Idaho EHDI is left unaware of the needs of these infants. An increase in communication and data sharing between Idaho EHDI, VR, and EI services allows all agencies to operate more effectively. Prompt notification of infants with hearing loss is vital to enable Idaho EHDI to track the infant and ensure each child receives appropriate and timely services.

All hospitals and midwiferies use the Idaho EHDI SRF to report infants who refer on their NHS and/or have risk indicators for hearing loss. Idaho EHDI cannot begin the tracking and follow-up process without receiving the SRF. It is crucial to receive 100% of the SRFs for referred infants, as this is the first pocket of LTF and the easiest point to address and decrease that risk. Currently Idaho EHDI receives 93% of SRFs. When a SRF is not received within two weeks, the Idaho EHDI Data Manager (DM) sends an email requesting the form. Idaho EHDI's goal is to receive 100% of SRFs. There is an ongoing need to educate hospital staff, train new hires on screening protocols, and provide support in order to maintain and improve this process.

Idaho EHDI works closely with the Audiology Consulting Team (ACT) to provide training on consistent screening and follow-up protocols in hospitals across the state to reduce LTF and ensure referred newborns receive timely follow-up testing. The ACT members also serve as liaisons to foster continuous engagement from hospital staff and works with hospitals on QI initiatives and PDSAs to accomplish Idaho EHDI goals and objectives. The ACT also helps mitigate the risk of program deterioration due to changes in hospital personnel, educates hospital staff to recognize the importance of timely reporting practices, and emphasizes the need to schedule follow-up testing for referred babies before discharge. This team has proven to be an invaluable asset committed to EHDI goals. They are a necessary component to the successful implementation of scheduling diagnostic evaluations for families before discharge from the hospital as the standard of care.

Due to a high percentage of low-income families and rural populations, providing equitable access to quality EI services is challenging. Service options are limited for families who enroll in Part C services as opposed to those with private intervention providers. There are only two certified Listening and Spoken Language (LSL) professionals in Idaho and neither provides services through ITP (Part C). There is a need to train and certify LSL professionals and expand available options for communication modalities for the families of infants with hearing loss. To better serve rural populations, it is imperative Idaho EHDI explore the use of tele-health as a delivery option for Part C services.

In the previous grant period, Idaho EHDI identified a downward trend of children with hearing loss enrolling in EI. In 2013, 56 of 60 families of infants that are D/HH (93%) enrolled in EI services, compared to 36 of 42 (86%) in 2014. In 2017, the number of families that enrolled

decreased to 29 of 47 (62%). Through a survey conducted by Idaho State University (ISU), it was shown that many parents are seeking services from private providers, thus leading to a decrease in children with hearing loss with an Individual Family Service Plan (IFSP). To ensure children identified with hearing loss are receiving services, there is a need for Idaho EHDI to explore strategies to elicit reporting practices from the private sector. Idaho EHDI will establish a reporting tool that will enable these providers to inform Idaho EHDI when they are delivering services to children with hearing loss. For this action to be successful, private providers must have a mechanism to report timely and correct data.

In Idaho, there is a noticeable lack of participation in the Medical Home Model regarding the management of hearing loss. Infants who undergo diagnostic evaluation and are diagnosed with middle ear pathology are normally referred to an Ear, Nose, and Throat (ENT) physician. Often, the middle ear pathology is treated successfully by an ENT physician, yet treatment details are not communicated to Idaho EHDI or the audiologist. Improved communication between the ENT physician, PCP, audiologist, and Idaho EHDI would prove effective in reducing Idaho's LTF and LTD rate. By creating a learning community(s) in conjunction with the Idaho chapter of the American Academy of Pediatrics (AAP), Idaho EHDI will improve pediatric healthcare by connecting healthcare providers, families, and interventionists with appropriate resources.

# Methodology

Universal screening is the first step to increasing EI enrollment rates. Idaho EHDI has been developing a NHS program since the year 2000. Subsequently, NHS has been accepted as standard of care and has been implemented in all 31 Idaho birthing facilities as well as five midwife clinics. All NHS programs in the state voluntarily report their screening data electronically through the Early Hearing Detection and Intervention Information System (EHDI-IS) web application. Over the past five years Idaho has maintained a 98% screening rate and a 3% referral rate.

Following a failed screening, each infant should receive a diagnostic hearing evaluation from a pediatric audiologist. Over the past five years, Idaho's LTF rate has decreased from 30% to 25% and still requires significant improvement. To address the high LTF rate, Idaho implemented several processes in Pilot Hospitals that have demonstrated a marked improvement in LTF rate.

Idaho EHDI discovered that many SRFs were not received by the program. The SRFs provide IDAHO EHDI with screening results of each infant that refers, their demographic information, and a Health Insurance Portability and Accountability Act (HIPAA) release that allows IDAHO EHDI to share screening information with the ITP (Idaho Part C), the IESDB, H&V (Family-to-Family Support), the infant's PCP, and their pediatric audiologist. The SRF initiates the tracking processes to ensure infants meet the 1-3-6 guidelines. Idaho EHDI implemented a statewide PDSA to request SRFs from birthing facilities when they have not been received by the program within two weeks of birth. This process has increased the percentage of received SRFs from 77% to 90.6%. Idaho EHDI plans to continue this successful PDSA into the new grant cycle.

Another follow-up procedure the program implemented is sending certified letters to families of

infants that refer on their NHS. After an infant refers on their NHS, their family is sent a letter informing them of their infant's NHS results and recommended next steps. Six weeks later the POC attempts to contact the family by phone. If the POC is unsuccessful, a certified letter is sent to the family to ensure they have the necessary information to find a pediatric audiologist in their area. In the previous grant cycle, IDAHO EHDI sent 432 certified letters and 309 have confirmed delivery; successfully educating 71.5% of families for whom diagnostic follow-up is indicated

In the previous grant period, IDAHO EHDI initiated a PDSA in two hospitals to schedule a diagnostic appointment with a pediatric audiologist prior to discharge for all infants that refer on their NHS. In one year, the Pilot Hospitals' LTF rates dropped from 25% to 11.43% and from 26.77% to 10.1%, respectively. Both Pilot Hospitals that implemented the PDSA used centralized scheduling and had an in-house audiology department. In 2015, Idaho EHDI spread the PDSA to two more rural hospitals that had neither centralized scheduling nor in-house audiology. Pilot Hospitals 3 and 4 saw reductions in their LTF rates from 54.55% to 44.44% and 47.54% to 32.65%, respectively. Currently, IDAHO EHDI has introduced this PDSA into twenty birthing facilities with mixed success. Thirteen of the birthing facilities schedule follow-up appointments infrequently. Still, their LTF rate has dropped from an average of 50.79% in 2016 to 22.62% in 2018. The LTF rate in the seven birthing centers that regularly schedule follow-up appointments was reduced from 21.79% in 2016 to 15.13% in 2018. Idaho EHDI intends to establish the PDSA in those birthing facilities not currently participating and increase the frequency of scheduling in the facilities where it has already been proven effective.

The family-centered care model is imperative if families are to take an active role in decision making regarding their health care needs. The PCP should coordinate care among the family's health care team in the method the family chooses. To accomplish this task effectively, PCPs must be informed of the patients' NHS results. Idaho EHDI now has access to Idaho's newborn screening database which has accurate records of an infant's PCP. When an infant refers on the NHS, Idaho EHDI sends a letter to their recorded PCP informing them of their patient's NHS results and suggested next steps.

In the upcoming grant period, Idaho EHDI will partner with St. Luke's Regional Medical Center to conduct a learning collaborative to educate PCPs on the prevalence of hearing loss and the importance of NHS. Primary Care physicians will learn about the nationally recognized 1-3-6 goals, the importance of identifying hearing loss as early as possible, risk factors for late-onset and progressive hearing loss, peer to peer information sharing, family-centered care model, collaborating with family-to-family support organizations, and data sharing. Learning collaboratives led by St. Luke's in the past have been attended by most Idaho pediatricians.

Family engagement is a vital component of a successful EHDI program. Idaho EHDI currently contracts with Idaho H&V to provide family-to-family support services to families of infants that have been diagnosed with hearing loss. When an infant is identified with hearing loss, Idaho H&V is notified that they need to contact the family. Once they contact the family (but no later than 48 hours, per Idaho statute) they pass the referral along to ITP and IESDB to set up a meeting to discuss Part C EI services. Idaho H&V continues to provide support to the family through the age of three.

Idaho EHDI partners with ITP and IESDB to connect infants with hearing loss to EI services. When an infant is diagnosed with hearing loss, they are referred to ITP. The Infant Toddler Program then coordinates a home visit with the family and a D/HH consultant from IESDB where they discuss the needs of the family and available communication options. Enrollment in Part C EI is highly encouraged at this meeting.

Idaho EHDI will work with ITP and IESDB to explore telehealth opportunities in our state. Outside of a few metropolitan areas, Idaho is extremely rural. Early intervention providers are required to drive long distances in order to provide necessary services to Idaho infants that are D/HH. The use of telehealth would reduce the strain on resources that delivering services to rural families currently necessitates.

Idaho EHDI has an engaged and committed multidisciplinary AC that has worked together for over ten years. The AC is pivotal in program planning and evaluation. Programs and stakeholders represented on the AC include: Parents of children that are D/HH, audiologists, university professors that instruct audiology and speech and language classes, ITP (Idaho Part C Coordinator), Title V and Children and Youth with Special Health Care Needs (CYSHCN), the Idaho AAP Executive Director, the AAP Chapter Champion, the IHA, IESDB, Idaho Head Start, and Idaho Child Find and Developmental Milestones. There are three parents of children with hearing loss and two members of the D/HH community on the AC.

### Work Plan

**Aim Statement 1:** Increase timely diagnosis of hearing loss by 30% (thirty percent) from baseline over 3 (three) years by obtaining 100% of SRFs for each infant that refers on their NHS by 1 (one) month of age.

The purpose of this objective is to obtain an SRF for each infant in Idaho that fails their NHS by the time the child reaches one month of age. The Idaho SRF contains vital information to track and monitor the progress through the EHDI system for each infant that fails their NHS. The information on the SRF includes demographic and contact information, NHS results, risk factors for delayed-onset or progressive hearing loss, follow-up appointment clinic, date, and time, and a HIPAA release that allows Idaho EHDI to share the infant's Protected Health Information (PHI) with the child's medical home, audiologist, Idaho's Part C program, IESDB, and H&V - GBYS. The follow-up appointment information on the SRF allows Idaho EHDI to set reminders in the EHDI-IS to follow up with the infant's family before they exceed the 1-3-6 EHDI timeline.

All Idaho birth facilities transfer screening records into the EHDI-IS by uploading their screening data bi-monthly through the EHDI-IS web application. The data upload transfers only certain data elements, including the infant's name, date of birth (DOB), Medical Record Number (MRN), birth facility, and screening results. The Idaho EHDI DM monitors and tracks all infants that fail their NHS from each birthing facility to ensure Idaho EHDI receives the demographic information necessary to contact families of infants that fail the NHS. When Idaho EHDI has not received SRFs for each infant that failed, the DM sends an email request for all missing SRFs to each birthing facility's screening program manager. Idaho EHDI is receiving SRFs for 85.6% of infants that fail the NHS. Idaho EHDI plans to increase the percentage of SRFs received to 100%

by the end of the grant period.

**Aim Statement 2:** Increase timely diagnosis of hearing loss by 30% (thirty percent) from baseline over 3 (three) years by scheduling diagnostic appointments for each infant that refers on their NHS prior to discharge in all birthing facilities in Idaho.

The purpose of this objective is to increase the likelihood that parents will bring their infants to get a diagnostic evaluation with a pediatric audiologist following two failed NHS. Idaho began this objective as a PDSA in two hospitals in 2014 and saw remarkable results. In the first year, Pilot Hospital 1 saw their LTF rate drop from 25% to 11.43% compared to the previous year. Pilot Hospital 2 saw their LTF rate drop from 26.77% to 10.1%. Idaho EHDI then expanded the PDSA to two additional hospitals in a rural area. Pilot Hospitals 3 and 4 saw their LTF rates drop from 54.55% to 44.44% and 47.54% to 32.65%, respectively.

When an infant fails two hearing screens, the screener educates the parent on the next steps in the EHDI process. When a birthing facility has an in-house audiology department, the screener simply schedules a follow-up appointment for the parent at a time of their convenience. If the birthing facility does not have in-house audiology, the screener uses Early Hearing Detection and Intervention – Pediatric Audiology Links to Service (EHDI-PALS) to generate a list of audiology clinics convenient to the parents. The screener calls the clinic selected by the parent and schedules an appointment for the infant. The audiology clinic, the appointment time, and date are recorded on the SRF and sent to the Idaho EHDI office. The Idaho EHDI DM records the appointment information in the infant's record in the EHDI database and sets a reminder to follow-up with the audiology clinic five days after the appointment date if diagnostic results are not received. If an appointment is missed, the POC contacts the parent and encourages them to schedule and attend an evaluation with a pediatric audiologist.

The PDSA has now been spread to 20 of Idaho's 31 birthing facilities; seven of which regularly schedule follow-up appointments and thirteen which do so infrequently. The LTF rate in the seven hospitals that regularly schedule follow-up appointments dropped from 21.79% in 2016 to 15.13% in 2018. The LTF rate in the hospitals that schedule infrequently was reduced from 50.79% in 2016 to 22.62% in 2018. In the upcoming grant period Idaho EHDI plans to introduce this PDSA to the remaining eleven hospitals and increase the frequency of scheduling in the hospitals already participating.

**Aim Statement 3:** Increase the percentage of children that are D/HH that are enrolled in Early Intervention (EI) prior to 6 (six) months of age to 80% (eighty percent) by referring every identified child to the Infant Toddler Program (Idaho's Part C) by March 31, 2024.

Idaho EHDI is housed in the same division as Idaho's Part C program enabling effortless referral to their program. All infants identified with hearing loss are referred to Part C EI within 48 hours of Idaho EHDI being notified of the infant's hearing status. All infants with hearing loss in Idaho are eligible for Part C services. In accordance with the Individuals with Disabilities Education Act (IDEA), Part C is required to have a signed IFSP signed within 45 days of referral and, per department policy, make every attempt to contact the family within seven days of referral. Idaho has been very successful in the past with enrolling infants with hearing loss into Part C EI.

10 Idaho Project Narrative

To capture EI enrollment data outside the Part C system, Idaho EHDI has collaborated with the Idaho EDHI-IS developers to create an online EI reporting tool. The EHDI-IS has very recently been updated to include the tool. A Speech-Language Pathologist (SLP) has been recruited to the ACT to assist with necessary pilot testing and troubleshooting.

Idaho State University and IESDB have been conducting annual EI assessments with families who participate in the Idaho Collaborative Assessment Project (ICAP). The data from the ICAP assessments are stored on ISU servers. Idaho EHDI will work with ISU to create a data linkage between the ISU servers and the EHDI-IS. Technical discussions have already begun, and a data sharing agreement is being reviewed by each party's legal departments. Data linkage will give Idaho EHDI access to reportable EI data for all infants tested during the ICAP process.

**Aim Statement 4:** Increase by 20% (twenty percent) the number of children that are D/HH that are enrolled in family-to-family support by referring every identified child to family-to-family support services by March 31, 2024.

With the help of Idaho EHDI and the Health Resources and Services Administration (HRSA), H&V established a GBYS in October of 2017. Since that time, Idaho EHDI's first referral is to the GBYS program when an infant is diagnosed with hearing loss. Guide by Your Side has attempted to contact every child referred to them, with a 55% success rate. In the upcoming grant period, a PDSA will be carried out to explore using text messaging to establish contact with families, in addition to phone calls. Idaho EHDI plans to continue their partnership with GBYS with the goal of increasing the enrollment rate to 75% in the upcoming grant period.

**Aim Statement 5:** Increase the number of EI providers by 5 (five) per year that report data to EHDI through the use of the HiTrack online reporting tool by March 31, 2024.

Idaho EHDI worked with their EHDI-IS developer to create an online reporting tool for private EI providers to report to Idaho EHDI when they begin delivering services to infants with hearing loss. A speech-language pathologist has been recruited to the Idaho EHDI ACT. Idaho EHDI will work with the SLP to develop reporting forms for EI providers and add those to the online reporting tool. Idaho EHDI will identify and educate private EI providers on the reporting process. Use of the reporting tool by private EI providers will be tracked by Idaho EHDI to monitor the frequency of use and ensure it is being used appropriately. A survey will be created and distributed to gauge the ease of use of the reporting tool by private EI providers. The results of the survey will be used to modify the reporting tool as needed.

**Aim Statement 6:** Increase by 10% (ten percent) the number of health professionals and service providers trained on key aspects of the EHDI program by conducting in-person trainings at all Idaho birth hospitals every other year by March 31, 2024.

Idaho EHDI contracts with a team of four audiologists referred to as the ACT. The audiologists are part of the largest hospital system in Idaho and have five pediatric clinics. Idaho has seven health regions and each audiologist is responsible for providing support to the birthing centers in

one or two regions. Each year, the audiologists provide training to half of the birthing centers in the region(s) for which they are responsible. Periodic training is necessary because of natural turnover of screening staff as well as to maintain and improve the staff's screening knowledge and clinical skills. The Audiology Consulting Team provides training on screening skills, Idaho EHDI reporting requirements, the use of the EHDI-PALS website, Idaho EHDI PDSAs, and reporting procedures. The Audiology Consulting Team also provides each birthing facility with technical support for and assistance with screening equipment.

**Aim Statement 7:** Increase the number of professionals engaged in the EHDI system by 10% (ten percent) by conducting annual inter-professional trainings by March 31, 2024.

Idaho EHDI is planning a workshop to train multiple D/HH professionals to work as a team to provide services to their mutual patients/clients. The workshop will include pediatric audiologists, pediatric SLPs, teachers for the deaf, Part C providers, and university students enrolled in audiology or speech-language pathology tracks. The three-day workshop will focus on the elements of the Idaho EHDI program and how it functions, how to educate families on communication options in an unbiased manner, cultural competence, and coordination of care. Continuing education credits will be available to entice various professionals to attend. The workshop will be held annually throughout the grant period.

Following the initial workshop, a quarterly conference call will be held to ensure professionals stay involved in the team approach to care. All professions listed above will be invited to participate. The conference call will give the attendees an open forum in which to discuss challenges associated with communicating their specialized advice to other professionals on their patient's care team.

**Aim Statement 8:** Increase the support network for children that are Deaf and/or Hard of Hearing (D/HH) by 20% (twenty percent) by conducting annual family support workshops by March 31, 2024.

Idaho EHDI has partnered with TCP for the past two years to bring a family-to-family support workshop to Idaho. The CARE Project conducts workshops focused on connecting families of children with hearing loss via counseling experiences aimed at processing the emotional stages of grief. The workshop brings together up to ten Idaho families to form a support group. Professionals (audiologists, SLPs, hearing technology experts, counselors, etc.) educate parents on hearing loss. Volunteers watch the children during these presentations. The volunteers are generally members of H&V, IESDB teachers, audiologists, EI providers, and university students. The families and volunteers have meals together to encourage lasting relationships. The families get to know each other and exchange contact information. Gathering professionals from the various occupations encourages coordination of care post-workshop. The parents of children with hearing loss. Reviews from the workshops have been overwhelmingly positive. **Aim Statement 9:** Increase the number of families connected with a D/HH adult by 10% (ten percent) by partnering with the IESDB and/or the Council for the Deaf and Hard of Hearing (CD/HH) by March 31, 2024.

More than 90% of children with hearing loss are born to two hearing parents. This deprives them of a role model that can ease the parents' apprehension and show that D/HH individuals can grow to be happy and successful adults. Idaho EHDI will work with IESDB and the Idaho Council for the Deaf and Hard of Hearing (CD/HH) to recruit D/HH adults that can conduct home visits, give access to American Sign Language (ASL), share positive Deaf life experiences, and teach advocacy skills. Once D/HH adults have been recruited to the program, Idaho EHDI will ensure families of infants diagnosed with hearing loss can connect with these individuals when they have questions about their child's future.

**Aim Statement 10:** Create a mobile application to track a child's progress through the screening, diagnosis, EI enrollment process, and coordinate their medical home by March 31, 2024.

The coordination of care of individuals with hearing loss has proven to be a major challenge. Idaho EHDI will create a mobile application that will not only track the child through the screening, diagnostic, and EI enrollment processes, but give families a way to identify who is in their medical home and what each entity does for their child. Many Idaho families have reported that they don't know who their EI provider is or that they know that someone comes to their house on a specific day, but they do not know what service that individual provides for their child. This app will allow them to take pictures of their providers and create a professional profile for each team member who works with their family. The app will also allow the family to upload diagnostic reports to their professionals' profiles. This will reduce confusion when one professional inquiries about what happened at their last visit with another professional on their team. The app will make it easier for a family to keep track of who is providing services for the D/HH child, facilitate communication between professionals, and improve coordination of care.

### **Resolution of Challenges**

**Aim Statement 1:** Increase timely diagnosis of hearing loss by 30% (thirty percent) from baseline over 3 (three) years by obtaining 100% of screening results forms for each infant that refers on their NHS by 1 (one) month of age.

Idaho EHDI requests an SRF from the birthing facility for every infant who refers on their NHS. Challenges include hospitals and staff not understanding the importance of sending screening results or neglecting to send them in a timely manner. Creating a point of contact for each birthing facility will ensure that the DM can email the appropriate person to request missing SRFs. Personnel turnover in birthing facilities occurs frequently. Thus, maintaining open lines of communication between Idaho EHDI and birthing facilities is vital to sustaining functioning partnerships. The ACT has close relationships with the NHS managers and is therefore able to stay abreast of staffing changes and provide timely education, technical support, and training to new staff.

**Aim Statement 2:** Increase timely diagnosis of hearing loss by 30% (thirty percent) from baseline over 3 (three) years by scheduling diagnostic appointments for each infant that refers on their NHS prior to discharge in all birthing facilities in Idaho.

Finding and accessing qualified pediatric audiology services poses challenges in rural areas of the state. Idaho EHDI has partnered with a clinic in northern Idaho providing diagnostic AABR equipment. Previously, families in this region had to travel to a neighboring state to obtain a hearing evaluation. There are still regions of the state where families must travel several hours to receive services. To mitigate this gap in services, Idaho EHDI will continue to bring pediatric audiology educational opportunities to audiologists focusing on underserved regions.

Idaho EHDI uses EHDI-PALS to identify available diagnostic centers. EHDI-PALS is an online resource for families and the medical home to find nearby audiology services. Audiologists must complete an annual online survey in order to be listed on EHDI-PALS. Challenges include insuring that qualified audiologists sign up on EHDI-PALS and renew their listing annually. Idaho EHDI is aware that several facilities listed on EHDI-PALS do not provide the services they purport to provide.

An additional challenge is the continual engagement of the ACT with hospitals to cope with personnel turnover. Embedding scheduling of the diagnostic evaluation after NHS referral needs to become a standard policy and procedure so that new screeners, discharge planners/nurses, and patient care coordinators/nurse navigators follow a consistent protocol.

The resolution to this challenge is continual involvement of the ACT with their regional hospitals. In addition, reminders to schedule diagnostic evaluations could be built into computer systems or written into protocols or policy and procedure manuals. These could be implemented into skills labs and learning modules so scheduling diagnostic evaluations prior to discharge becomes the standard of care. The ACT could attend in-services for hospital staff to explain the diagnostic evaluation appointment protocol.

A process has been developed to increase the rate of timely diagnostic results received by Idaho EHDI. The Data Manager has developed a system to issue bi-weekly email reminders to all audiology clinics. The Data Manager currently receives 67% of diagnostic results within a five-day period. This allows the POC to contact families within a week of their missed diagnostic appointment.

Audiologists new to Idaho are not always aware of EHDI reporting processes. Idaho EHDI is now using the Bureau of Occupational Licenses' website to identify newly licensed audiologists and sending them a welcome letter along with JCIH recommended protocols, reporting guidelines, and access to educational resources and connections to family support programs, as well as EI services.

**Aim Statement 3:** Increase the percentage of children that are D/HH that are enrolled in Early Intervention (EI) prior to 6 (six) months of age to 80% (eighty percent) by referring every identified child to the Infant Toddler Program (Idaho's Part C) by March 31, 2024. To identify all infants receiving EI services, an online EI reporting tool has been developed. In the upcoming grant period, it will be distributed and utilized by EI providers throughout the state. To obtain accurate reporting, education to EI providers will need to be conducted on the purpose and mechanism.

Barriers include identifying and educating EI providers on the reporting tool and procedures. This will be mitigated using experiences learned by Idaho EHDI on reaching pediatric audiologists. Idaho EHDI will identify potential EI providers through state licensing agencies. Idaho EHDI will survey providers on educational needs, identify training opportunities, and implement reporting along with evaluation.

**Aim Statement 4:** Increase by 20% (twenty percent) the number of children that are D/HH that are enrolled in family-to-family support by referring every identified child to family-to-family support services by March 31, 2024.

The Hands and Voices GBYS program went through a significant change in administration in the spring of 2019. Both the GBYS Director, Guide Coordinator, and all but two (2) guides were replaced, resulting in a substantial shift in leadership. The ISB coordinator has worked with the new GBYS leadership to ensure that all members have been trained according to the national GBYS guidelines, including non-biased communication options. The program appears to have stabilized and ISB intends to continue to provide consultation and guidance to ensure an enduring and effective family-to-family support program.

Another significant barrier is receiving authorization from the family to refer infants diagnosed to hearing loss to the GBYS program. Many families in Idaho choose not to access "state" services and decline to sign a release form. Under the Health Insurance Portability and Accountability Act, without the signed release form, ISB is unable to refer the family to the GBYS program. Between 2017 and present ISB was unable to refer 41 infants (39%) with hearing loss to GBYS. Idaho EHDI works with screening programs in birthing facilities to educate them on the importance of receiving a signed release form.

Aim Statement 5: Increase the number of EI providers by 5 (five) per year that report data to EHDI through the use of the HiTrack online reporting tool by March 31, 2024.

To identify all infants receiving EI services, an online EI reporting tool has been developed. In the upcoming grant period, it will be distributed and utilized by EI providers throughout the state. To obtain accurate reporting, education to EI providers will need to be conducted on the purpose and mechanism.

Barriers include identifying and educating EI providers on the proper use of the online reporting tool. This will be mitigated using experiences learned by Idaho EHDI on reaching pediatric audiologists. Idaho EHDI will identify potential EI providers through licensing agencies. Idaho EHDI will survey providers on educational needs, identify training opportunities, and implement reporting along with evaluation.

**Aim Statement 6:** Increase by 10% (ten percent) the number of health professionals and service providers trained on key aspects of the EHDI program by conducting in-person trainings at all Idaho birth hospitals every other year by March 31, 2024.

The only significant barrier to accomplishing this goal is finding a mutually convenient time and date for the ACT member and each screening program to conduct the training. Idaho Sound Beginning's Health Information Specialist (HIS) works closely with the primary contact in each screening program to coordinate a time and date for the training to take place.

**Aim Statement 7:** Increase the number of professionals engaged in the EHDI system by 10% (ten percent) by conducting annual inter-professional trainings by March 31, 2024.

Idaho EHDI has sought and received buy-in from all professions listed in the work plan to participate in this training which will be initiated in January 2020 and no challenges to carrying out the workshop are anticipated. Maintaining attendance at the quarterly conference calls could prove challenging because of the demanding schedules of targeted professionals. Idaho EHDI will survey the participants to find a time to hold the calls that will yield the highest rate of participation.

**Aim Statement 8:** Increase the support network for children that are Deaf and/or Hard of Hearing (D/HH) by 20% (twenty percent) by conducting annual family support workshops by March 31, 2024.

Idaho EHDI has partnered with TCP to bring this workshop to Idaho families for the past two years and plans to continue the collaboration. The most significant challenge realized over the past two years was recruiting enough volunteers. Idaho EHDI has compiled a list of volunteers from the previous years and expects the challenge of recruiting volunteers to decrease with every consecutive workshop.

**Aim Statement 9:** Increase the number of families connected with a D/HH adult by 10% (ten percent) by partnering with the IESDB and/or the Council for the Deaf and Hard of Hearing (CD/HH) by March 31, 2024.

The only challenge Idaho EHDI has identified to achieving this goal is recruiting appropriate deaf adults to participate. Idaho EHDI plans to work with IESDB and CD/HH to locate suitable deaf adults for the program.

**Aim Statement 10:** Create a mobile application to track a child's progress through the screening, diagnosis, EI enrollment process, and coordinate their medical home by March 31, 2024.

Idaho EHDI foresees Information Technology (IT) resources within DHW as the major challenge to achieving this goal. Initial exploration has already begun, and it appears the DHW IT department does not employ anyone with experience creating mobile applications. Idaho EHDI will search for experts outside the state resources to address this hurdle. Ensuring that data collection through the mobile application is done in a HIPAA-compliant manner is another challenge. Idaho EHDI has consulted with the DHW HIPAA Compliance Officer to guarantee no individual's rights are violated by using the mobile application. Idaho EHDI will remain in constant contact with the HIPAA Compliance Officer throughout the development of the mobile application.

### **Evaluation and Technical Support Capacity**

Idaho EHDI works with 31 birthing facilities and five midwife clinics throughout the state. All programs report their NHS data through the EHDI-IS web application. Facilities report the following on every infant born in their facility: MRNs, first and last name, DOB, birth order, birth facility, gender, and screening results. Idaho EHDI partnered with VR to create an interface that transfers all demographic and screening data from VR's software system to Idaho's EHDI-IS. This data transfer occurs weekly and includes all information from two weeks prior, which gives birthing facilities the necessary time to report data to VR. This information is compared and/or combined with what is entered into the EHDI-IS to ensure accurate data. Idaho is now receiving data for 100% of the state's births.

The EHDI-IS enables Idaho EHDI to track infants' progress through the 1-3-6 timeline and ensures that every infant who refers on the NHS receives a follow-up hearing evaluation, and if necessary, EI. The Idaho EHDI-IS includes a feature to set reminders for the EHDI program to follow up with families who exceed the 1-3-6 timelines. When Idaho EHDI has not received diagnostic reports within five days of an infant's scheduled diagnostic appointment, the results are requested from the audiology clinic where the appointment was scheduled. If the family did not attend the appointment, the Idaho EHDI POC contacts the family and encourages them to attend a pediatric hearing evaluation. When an infant is diagnosed with a hearing loss, the diagnosis is entered into the EHDI-IS and a referral is immediately made to ITP and GBYS. Once the infant enrolls in EI services, the record in the EHDI-IS is updated to reflect the services they are receiving.

The EHDI-IS includes features that aid the EHDI program in data cleaning. The Duplicate MRN report creates a list of all entries with identical MRNs, enabling Idaho EHDI to ensure that duplicate entries are removed from the EHDI-IS. The EHDI-IS also has a Probable Duplicate report that creates a list of entries that are similar enough to appear to be duplicate entries. Many of these represent twins and hence require manual review to ensure accuracy.

Idaho EHDI created a data interface between the Infant Toddler Program Key Information and Data System (ITPKIDS – Idaho's Part C data system) and the Idaho EHDI-IS. It was identified that additional data not currently being gathered could be utilized and documented by each program. Data fields were added to ITPKIDS to collect salient information. The modifications included "match screens" to verify the infants in each system were, in fact, identical infants prior to combining the two records. This interface allows Idaho EHDI and ITP to share information seamlessly. The data transfer runs nightly and transfers demographic data, as well as screening and diagnostic audiology results, between the two systems.

Idaho EHDI uses Microsoft Excel to track and evaluate all PDSAs that cannot be tracked using

the EHDI-IS. Excel is an ideal program for recording data and displaying it in a way that is easy to understand. It is also an excellent tool for displaying the impact of the PDSAs over time. Excel spreadsheets are used to create baseline data and then record the results after an intervention has been introduced. The spreadsheets are converted into run charts that show the intervention's impact over time. Excel will be used to track the progress made with the learning communities and the care coordination plans in the upcoming grant period.

When qualitative data is the best way to measure the outcomes of PDSAs, surveys will be used to gauge the effectiveness of the intervention. Spreadsheets cannot accurately capture parents' willingness to participate in the next learning community or satisfaction with family-based support groups or organizations. Using surveys will help Idaho EHDI assess whether the implemented interventions are improving the quality of family-based parent support groups and leadership positions.

The Idaho EHDI team comprises four individuals with complementary skills and levels of experience. The Idaho EHDI Coordinator has worked with the program for eight years. He began working with the program as the DM and progressed to the coordinator position five years ago. He has built relationships with partnering organizations across the state that collaborate with the program to achieve the 1-3-6 EHDI goals. He has been a member of the board of Idaho CD/HH for five years and works with them when the initiatives of both programs align.

The Parent Outreach Coordinator/Parent Champion, who in addition to being a registered nurse is also the mother of two children with hearing loss, has been a member of the Idaho EHDI team for twelve years. The Parent Champion is an invaluable resource for Idaho EHDI. She contacts the parents of infants who refer that delay getting diagnostic testing. She explains to them the need for testing as well as the testing process itself. She also works relentlessly to locate infants in need of follow-up. She can connect with parents on a personal level and is incredibly influential with them.

The Health Information Specialist (HIS) has been working with the program for nine years. The HIS has employed her skills to make constant contact with NHS coordinators in every birthing center in Idaho. Another of her vital skills is utilizing these personal connections to locate infants to ensure that they receive the necessary diagnostic testing. The HIS is also bilingual; speaking both Spanish and English. This ability enables Idaho EHDI to collect data from the large Hispanic community in Idaho, as well as direct them to the screening/ diagnostic testing that meets their needs.

The Data Manager has been employed with Idaho EHDI for two years. The DM has used his experience with all Microsoft Office programs to create spreadsheets that take raw data and convert it into usable information, create letters for contacting parents and PCPs, and to create PowerPoint presentations used at conferences. The DM works closely with the ACT to provide data in a meaningful way to work with NHS programs in hospitals, midwiferies, EHS programs, and community centers to improve the quality of their individual programs.

Idaho EHDI contracts with a team of audiologists, the ACT. The ACT conducts trainings in every screening program in Idaho every other year, at minimum. The ACT also aids Idaho EHDI

in initiating PDSAs in birthing facilities across the state. The ACT is instrumental with the 'Scheduling Appointments' PDSA in Aim Statement 2 of the Work Plan. The Early Hearing Detection and Intervention Program – Pediatric Audiology Links to Service app is also used in this PDSA. After an infant refers on the NHS, EHDI-PALS is used to locate a pediatric audiology clinic convenient for the family and schedule an appointment. The appointments are recorded in the EHDI-IS and reminders are set to enable the EHDI team to follow up when expected diagnostic results are not received by the program. The ACT supports Idaho EHDI in the planning and execution of PDSAs as well as general program evaluation.

Idaho EHDI has a multidisciplinary AC that has been working together for seven years. The AC comprises stakeholders from across the medical community. There are representatives from Idaho Part C, IHA, Title V and CYSHCN, the AAP, IESDB, Idaho Head Start, Idaho Child Find, and Developmental Milestones. Twenty-five percent of the AC are members of the D/HH community (three parents of children with hearing loss, and two people with hearing loss). The AC is essential to initiating, executing, and spreading PDSAs across the state. The AC meets quarterly where they work together to guide the EHDI program. At the quarterly meetings, the AC is presented with data gathered from the ongoing PDSAs and, when necessary, helps modify them to be more efficient. Once a year, the AC conducts a comprehensive program evaluation to enhance the strengths of the program and identify and outline strategies to eliminate weaknesses.

### **Organizational Information**

Idaho EHDI's mission is to maintain and enhance an effective and sustainable EHDI program for Idaho which ensures that infants with hearing loss are identified early, and appropriate intervention services are initiated to enable them to access and achieve communication and social skills commensurate with their cognitive abilities. Idaho EHDI fosters partnerships with stakeholders to ensure accessibility and quality standards. Idaho EHDI oversees a protected and secure EHDI tracking system capable of supporting program goals. Idaho EHDI is committed to providing education and connection to resources, ensuring families can achieve their goals.

The EHDI Program is part of the Idaho DHW, Division of FACS, and is housed within ITP. The DHW's programs and services are designed to improve Idaho residents' lives and their mission includes the protection of public health. The Family and Community Services division is responsible for Developmental Disability and Child Welfare services.

The Infant Toddler Program is Idaho's Part C program for infants and toddlers age birth to three with developmental delays or disabilities and those with conditions that have a high probability of resulting in a developmental delay, including hearing loss. Children with any type or degree of hearing loss are eligible for enrollment in ITP.

The Infant Toddler Program is charged with ensuring that each eligible infant and toddler receives appropriate and timely EI services, and the program provides service coordination for each child. Service delivery may be provided by multiple agencies, including IESDB, which shares responsibility for serving these infants and toddlers.

The inclusion of a "Child Find" component designed to identify, locate, screen, and monitor

eligible infants and toddlers is a federal requirement for Part C programs. Idaho EHDI partners with the Infant Toddler (Part C) Child Find program in a coordinated effort to locate children with hearing loss and those at risk for LTF after their NHS. The Infant Toddler Program is able to provide OAE hearing screenings to out-of-hospital/midwife births and is working with Idaho EHDI on further outreach activities focused on increasing midwife referrals for hearing screens.

If disabilities with high probability for eligibility for ITP services are noted on a hearing screening referral form, Idaho EHDI immediately refers the infant to ITP for developmental assessment. Follow-up information on hearing issues or screening and diagnostic testing results are shared seamlessly between the ITP database and the Idaho EHDI-IS through an interface created in a previous grant period.

As part of the Idaho EHDI POC efforts, families at risk of becoming LTF are contacted and referred to ITP if financial or other impediments to the completion of diagnostic hearing testing exist. If the POC cannot contact the family, Idaho EHDI sends each infant's family a certified letter containing the educational information about diagnostic follow-up testing and how to locate a pediatric audiology clinic close to their residence or place of work.

The Idaho EHDI HIS coordinates tracking efforts with the ITP Child Find coordinator. The individual ITP service coordinator is sent a reminder letter to ensure that any ITP enrolled infant with risk factors for late-onset or progressive hearing loss or any infant who has not received any needed testing receives appropriate and timely monitoring and follow-up. The Infant Toddler Program has added several data fields to their data system in an effort to improve documentation and reporting of hearing screening and hearing status information.

The Idaho EHDI DM works closely with the ACT to develop and refine reports that are used to guide hospitals with NHS programs. The Data Manager uses the data from each individual hospital, including screening rates, refer rates, and LTF rates, to identify trends that the ACT can use to locate pockets of LTF that they can address with the hospital's NHS coordinator. The current Idaho EHDI staff and consultants were part of the National Initiative for Children's Health Quality (NICHQ) collaborative process and implementation and are familiar with QI process and the use of the PDSA procedures.

The Infant Toddler Program renewed their MOA with IESDB to provide EI services in 2016.

The MOA provides for (at a minimum):

- The coordination of referrals for infants and toddlers with hearing and/or vision loss.
- The inclusion of IESDB in the development of the IFSP and team meetings.
- The coordination of multi-disciplinary evaluations.
- The provision of information and services in a culturally sensitive manner and in the native language of the child and family unless clearly not feasible.
- HIPAA-compliant data sharing.

The Idaho EHDI AC meets quarterly to review program status and provide guidance and support to the program. The AC members include: The Executive Director of the Idaho Chapter of the AAP; The Part C Coordinator from the Infant Toddler Program; the Director of Outreach for

IESDB and representatives of IHA; the Idaho AAP Chapter Champion who is a neonatologist; representatives from the Bureau of Clinical and Preventative Services and Children's Special Health Services (Title V Block Grant); the Executive Director of the CD/HH; four consulting audiologists (ACT); a representative from ISU's audiology program; a representative from ISU's speech-language program; a parent representative; and five parents or individuals who are D/HH.

Regular education on Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis and PDSA processes are provided annually to the AC.

Other examples of support include:

- The Idaho Hospital Association's agreement to reissue its statement supporting EHDI and encouraging member/provider partnership with Idaho EHDI. This includes the sharing of NHS data to enable program tracking and follow-up. This is particularly important as Idaho has no legislative mandate, making provider participation voluntary.
- The granting of a conference session to present during the yearly Idaho Perinatal Project in conjunction with the Idaho Chapter of the AAP annual conference.
- Vendor space at many professional events such as the Idaho Medical Association Conference, the Idaho Nurse Association Conference, the Idaho Academy of Family Physicians Conference, and the Nurse Practitioners of Idaho Conference.

Future endeavors with AC include a working definition of "quality EI," the possibility of developing an app to convert the AAP "Roadmap to Families" (Attachment 7.4) into a mobile application that is family friendly and developing a learning community to facilitate the next steps for parents.

Idaho EHDI collaborates with the Head Start Collaboration Director in order to encourage and support the implementation of ECHO hearing screening programs for the EHS population. Six Head Start programs have implemented ECHO programs using OAE equipment. Idaho EHDI is continuing this relationship and plans to provide audiology support and training for the Head Start screeners. This is ongoing outreach, especially to MHS. The Migrant Head Start program serves a very high-risk and transient population. Approximately one half of this population is Hispanic. The program includes eleven centers covering the entire southwestern expanse of the state. Idaho EHDI works with the Head Start health coordinator to ensure this program has the equipment and support to continue OAE screening programs throughout their service area.

Idaho EHDI has one bilingual staff member and has access to additional interpreting services through the division of FACS. The State provides a toll-free CareLine with interpreting services. Parents of children with identified hearing loss, or those needing assistance, are immediately referred to their regional ITP (Part C) representative where they have access to services in their native language. The regional ITP translator will also assist the Idaho H&V family support group when needed. EHDI Program brochures, forms, and several handouts are available in English and Spanish. Translation of other materials is needed as well as information in Spanish on the Idaho EHDI website during the upcoming project period.