

## PROJECT NARRATIVE

### INTRODUCTION

NOTE: Acronyms used in this grant can be found in Attachment 8.

The Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program has established a comprehensive and coordinated statewide Early Hearing Detection and Intervention (EHDI) system of care that is targeted towards ensuring that newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis, and early intervention (EI). This work aligns with the purpose of funding opportunity number: Health Resources and Services Administration (HRSA) -20-047. NE-EHDI will build upon the accomplishments, relationships, and resources of the NE-EHDI system that have been developed in NE since 2000, and expand to encompass the entire funding purpose to include serving young children up to 3 years of age who are Deaf or Hard of Hearing (DHH) to receive appropriate and timely services that include hearing screening, diagnosis and EI.

The Infant Hearing Act of 2000 (Neb. Rev. Stat. §71-4735) specifies four purposes for the EHDI system in NE; which provide the foundation for the EHDI program to successfully achieve the objectives of this notice of funding opportunity (NOFO):

- To provide early hearing detection of hearing loss in newborns at the birthing facility, or as soon after birth for those children born outside of a birthing facility.
- To enable these children and their families and other caregivers to obtain needed multidisciplinary evaluation, treatment, and intervention services at the earliest opportunity.
- To prevent or mitigate the developmental delays and academic failures associated with late detection of hearing loss.
- To provide the state with information necessary to effectively plan, establish, and evaluate a comprehensive system for the identification of newborns and infants who have a hearing loss.

NE-EHDI will describe in this application how the program will utilize the funding to address the following activities aligned with the EHDI Act of 2017:

- Lead efforts to engage and coordinate all stakeholders in the state/territory EHDI system to meet the goals of this program.
- Engage, educate, and train health professionals and service providers in the EHDI system.
- Strengthen capacity to provide family support and engage families with children who are DHH as well as adults who are DHH throughout the EHDI system.
- Facilitate improved coordination of care and services for families and children who are DHH through the development of mechanisms for formal communication, training, referrals and/or data sharing between the state/territory EHDI Program and early childhood programs including the Individuals with Disabilities Education Act (IDEA) Part C program.
- Participate in the Annual EHDI Meeting and work with the HRSA-20-048 program recipient (the EHDI National Technical Resource Center (NTRC)) to implement the various initiatives that are listed in this NOFO and outlined in the work plan.

The mission statement of the NE-EHDI Program was developed to ensure newborns and infants who are identified as DHH, and their families, receive appropriate and timely high quality services. The mission

statement states: *The Nebraska Early Hearing Detection and Intervention Program develops, promotes, and supports systems to ensure all newborns in Nebraska receive hearing screenings, family-centered evaluations, and early intervention as appropriate.* The mission statement will be discussed during the advisory committee to add infants, and children up to age three to the target population.

To support the focus of the EHDI Act of 2017, the NE-EHDI system will continue to focus on newborns and expand to include children up to 3 years of age to receive hearing screenings, diagnostic evaluations, and EI. Work will continue with engagement of Primary Health Care Providers (PHCP) including the medical home, professional development, quality improvement, family-to-family support through family engagement and education, and expand to include DHH adult consumer-to-family support.

The goal of this funding opportunity is to support the development of state/territory programs and systems of care to ensure that children who are DHH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development.

This application will also describe how NE-EHDI will focus on the funding goal to achieve, collect, and report on the following objectives: By March 2024:

*Using the state/territory's data from the 2017 CDC (Centers for Disease Control and Prevention) EHDI Hearing Screening and Follow-up Survey (HSFS) as baseline data:*

- Increase by 1 percent from baseline per year, or achieve at least a 95 percent screening rate, whichever is less, the number of infants that completed a newborn hearing screen no later than 1 month of age.
- Increase by 10 percent from baseline, or achieve a minimum rate of 85 percent, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.
- Increase by 15 percent from baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.

*Using data collected from year 1 as baseline data:*

- 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.
- Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.
- Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.

To reach the NE-EHDI goals stated in the Methodology section of this application, that are aligned with the purpose, goal and objectives of the funding opportunity, the NE-EHDI Program will continue to further develop and implement the following strategies:

- Increase the awareness of parents/public and professionals about the importance and timeliness of newborn hearing screening, including early childhood hearing screenings, diagnosis, EI, family support, and the benefits of a patient/family centered medical home and family engagement.
- Involve and engage family partners in the planning, evaluation and improvement of the EHDI Program.
- Provide and promote appropriate use of parent resources and materials that are linguistically, culturally, and educationally appropriate.

- Increase knowledge about newborn hearing screening of staff in birthing facilities to more effectively screen hearing, share information about hearing status with patients/clients, and provide referral information as appropriate.
- Educate health professionals and service providers about 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.
- Strengthen existing and develop new collaborative approaches to link the providers of EHDI services, enhance care coordination planning, family-to-family support and DHH adult-to-family support services.

Beginning in 2004, the NE-EHDI Program began the development of an electronic data reporting and tracking system. In 2007, the NE-EHDI Program reporting and tracking system was rolled out as an integrated module of the State's Vital Records Electronic Registration System (ERS-II) developed by Netsmart Technologies. The data system includes hearing information on all the babies born in NE since 2007 and is designed so the majority of the data is generated from the birth certificate registry system with limited data entry by hospital personnel for hearing screening results or non-screening details.

One hundred percent of the NE birthing facilities provide newborn hearing screening and over 99 percent of newborns have their hearing screened during birth admission. All of the birthing facilities, regardless of size, have been conducting newborn hearing screening since 2003 and the hearing of nearly 99 percent of newborns has been screened during birth admission since 2005.

NE-EHDI performance regarding the 1-3-6 goals has improved and in many cases exceeded national performance levels from 2008-2016:

- All newborns completing a hearing screen by 1 month of age stayed in the range of 97.4 percent - 97.7 percent from 2008-2016, which is higher than the national average at 94.8 percent. (Increased nationally from 92.1 percent in 2008 to 94.8 percent in 2016.)
- Completed a diagnostic audiological evaluation by 3 months of age decreased from 70.5 percent in 2008 to 58.7 percent in 2016. (Increased nationally from 68.1 percent in 2008 to 75.9 percent in 2016.) Although, NE-EHDI has seen an increase in 2017 at 62.8 percent and 2018 at 71.5 percent. 2018 data is preliminary data and may change before the data is reported to the CDC 12/16/19. NE-EHDI credits the collaboration efforts with H&V/GBYS as one reason for the improved percentage of infants diagnosed by 3 months of age.
- Enrollment in EI services for those identified to be DHH by 6 months of age decreased from 82.4 percent in 2008 to 78.0 percent in 2016, but is still higher than the national average. (Increased nationally from 68.1 percent in 2008 to 75.9 percent in 2016.) It stayed at 78.0 percent in 2017 and the 2018 preliminary data increased to 86.0 percent.

As reported by the CDC, NE-EHDI loss to follow-up/loss to documentation (LTF/LTD) for diagnosis in 2008 was 40.2 percent, which was better than the national average of 43.3 percent and improved to 11.6 percent in 2018 compared to the national average of 18.1 percent. CDC only shows diagnosis LTF/LTD in 2008. Starting in 2015, CDC breaks down LTF/LTD by screening/diagnosis/early intervention.

Various services are available for children identified as DHH in NE. The Early Development Network (EDN), the Part C Early Intervention Program in NE, is one of the main services for those infants who were

born and reside in NE. In 2017 (most recent HSFS data reported), 51 were diagnosed as DHH and 43 were referred to EDN for EI (8 were not eligible for services). Another service for NE families is the Medically Handicapped Children's Program (MHCP). This program, under the Nebraska Department of Health and Human Services (NE DHHS), offers coordination/case management, access to specialty physicians, and payment of treatment services.

There is also a family support network available to families of young children identified as DHH. The four RPSDHH have provided professional-driven family support activities since 1997. The Parent Training and Information-Nebraska (PTI-NE) Program, which includes Family Voices in NE provides family support services for children with disabilities generally but not specifically targeted for DHH. Nebraska Hands and Voices (NE H&V) was organized in 2006 with financial assistance from the NE-EHDI Program. In 2013, the NE H&V Chapter established a Guide By Your Side (GBYS) Program. Collaboration with NE-EHDI and H&V/GBYS expanded in 2017 with a contract for a GBYS parent/staff to assist part-time with NE-EHDI follow-up for parents and medical professionals, care coordination and connecting parents with family support. The collaboration with H&V/GBYS is an opportunity for families statewide to connect with a parent guide with their first EHDI contact, and then be connected with the parent guide in their area. Families can learn from veteran parents about the challenges as well as the joys of raising a child who is DHH. The guides are parents of a D/HH child who have been trained to provide support and advocacy for other families. They respond to the family's individual needs to assist in helping their child reach their full potential.

The NE-EHDI Program established a multidisciplinary program advisory committee of stakeholders in 2001 and the active committee continues to meet biannually. The NE-EHDI Advisory Committee is culturally and geographically representative of stakeholders with an interest and concern for newborn hearing screening which includes parents, birthing facilities, pediatric audiologic diagnostic facilities, primary care providers, medical specialists, EI, family-to-family support, and the DHH community. The committee is comprised of 25 percent parents/family members of infants/children who are DHH and /or DHH individuals.

### **NEEDS ASSESSMENT**

Nebraska (NE) is a state that covers a large geographic area, but has a smaller population base. Much of the population is located in the eastern half of the state. Measuring 387 miles across with a total area of approximately 77,000 square miles, 45.8% of the state's population reside in the population centers of Omaha and Lincoln in the east with populations larger than 250,000. In contrast, 34 of the 93 counties statewide are defined as an area with low population density (6 or fewer persons per square mile), residing a large distance from a population center or specific service, requiring long travel time to reach a population center or service.

NE has also been experiencing shifts in the demographic make-up of the state over the 2000 to 2018 time period, according to the U.S. Census. In terms of increased diversity, NE has seen its minority population grow 91% during this time – which represents 21.5% of the total population. These demographic shifts can have significant implications for healthcare delivery, creating a need to focus on services that are culturally and linguistically appropriate.

In addition to providing services that are culturally and linguistically appropriate overall, health care providers should be aware of the specific minority populations that exist in their areas to address existing

health disparities. While this is a standard of care that all providers should adhere to, there is an increased stress on providers in the eastern part of the state, where an average population increase of over 26% between 2000 and 2018 has occurred. Migration of the younger population (18 to 45 years) from western parts of NE has primarily affected the Douglas, Sarpy (Omaha), and Lancaster (Lincoln) counties.

Within its minority populations, NE has seen a large increase in the Hispanic American population, which has more than doubled from 94,425 in 2000 to 215,872 in 2018 (128.6% increase) according to the U.S. Census estimates. Hispanic Americans now comprise 11.2% of the state's population. Asian and Pacific Islander populations grew during 2000 to 2018 by 132%; and the African American population has grown by 41%. Similarly, the Native American population in NE has increased by 83.3% during the same time period. Though many of Nebraska's Native Americans live on reservations, the majority do not. The urban areas of Omaha and Lincoln account for where more than 35% of the state's Native American population live, although they make up only a small proportion of these counties' total populations. A sizable number of Native Americans also reside in the northwestern part of NE adjoining the Pine Ridge Reservation in South Dakota.

As in other states, health disparities exist in NE, and unfortunately are present in many issues relevant to maternal and child health. Though African Americans make up only 5% of the NE population, they have a significantly disproportionate share of health burden and poor outcomes. According to the DHHS Vital Records, in 2016, the infant mortality rate (expressed as per 1,000 live births) among African Americans was 12.29, compared to that among the White population at 4.37 (approximately 2.4 times higher rate). Additionally, the preterm birth rate for African Americans was 13.35 compared to a rate of 8.99 for the White population, and they are 1.5 times more likely to be obese and have a 15.5 times higher incidence of sexually transmitted disease as compared to Whites. American Indians in NE have a 3 times higher rate of inadequate prenatal care. NICU admitted infants need longer term EHDI follow-up due to risk factors. Also, the parents of infants who are medically fragile may be addressing several health issues with their child that can cause stress and anxiety, which can make it more challenging for them to complete EHDI follow-up.

NE DHHS, Title V assists in facilitating the ongoing, systematic engagement which is needed to address these challenges. Title V has established relationships with key stakeholders to ensure that the public health and direct care infrastructures have culturally and linguistically appropriate services (CLAS) and health equity standards in place to inform how staff interact with clients, and that services are offered in a family-centered, comprehensive way. NE-EHDI receives funding from NE Title V and partners with several of the programs who are also Title V partners.

The systems of care present in NE to meet the needs of underserved and vulnerable populations includes a health care infrastructure that is based upon the low population density in much of the state. Rural areas have difficulty recruiting and retaining providers and health care professionals, and also in supporting facilities such as hospitals or other comprehensive care centers. These challenges have resulted in a proliferation of shortage areas throughout the state. The NE DHHS Office of Rural Health tracks the federally-designated Health Professional Shortage Areas (HPSA) as well as state-designated shortage areas by discipline. As of January 2019, nine full counties were federal HPSA for both the primary care and OB-GYN disciplines. There are far more counties identified as state-designated shortage areas; in April 2019, 64 counties out of 93 had this designation for the Family Practice discipline, and 85 full counties had

this designation along with portions of those surrounding Lancaster and Douglas counties for the OB/GYN discipline. There are 86 counties out of the 93 who have shortage areas for pediatricians.

To address these shortage areas, there are facilities located in federal shortage areas that specifically address providing affordable and accessible primary health care services, such as Medicare-certified Rural Health Clinics (RHC), Community and Migrant Health Centers (CHC), and Indian Health Service funded clinics. As of February 2018, there were 141 RHC, 7 CHC, and 8 IHS funded clinics, which have a main focus on assisting underserved areas.

Nebraska's geography and population distribution also impacts the availability and accessibility of specialty medical and audiology services for infants who need diagnostic evaluations. The screening protocol promoted by the NE-EHDI program still includes an outpatient hearing screening prior to a hearing evaluation at an audiology clinic. This protocol reduces the cost for families as well as utilizes the health care facilities more efficiently since NE pediatric audiologic diagnostic facilities are limited. Audiologists and medical specialists tend to be disproportionately clustered in the two major metropolitan areas in eastern NE, resulting in decreased availability for other areas of NE for pediatric diagnostic evaluations and treatment of children who are DHH. Over two-thirds of the audiologists and pediatric health care providers (physicians, physician's assistants, nurse practitioners, and otolaryngologists) practice within these two metropolitan areas. To address this issue, NE-EHDI led a learning community which resulted in implementing tele-audiology in NE in 2019. The Educational Service Unit (ESU) #13 in Scottsbluff is the spoke site and the University of Nebraska-Lincoln (UNL) Barkley Speech Language Hearing Clinic in eastern NE is the hub site. The Nebraska Department of Education (NDE) provided funding through a grant to UNL to pay for the tele-audiology equipment. Customer satisfaction surveys are being utilized to monitor and make improvements as needed.

Even though NE has approximately 72 audiologists who can serve pediatric patients at 29 sites, some of these clinics may not see any pediatric patients for a few years. There are only five sites who routinely provide pediatric audiologic diagnostic services. Three audiology facilities conducted approximately 86% of the diagnostic evaluations in 2018. Boys Town National Research Hospital in eastern NE conducts the majority of initial or confirmatory diagnostic evaluations in the state. The lists of pediatric audiology services in NE and surrounding areas can be accessed on the NE-EHDI website. This information and more is available through the national EHDI-PALS ([www.ehdipals.org](http://www.ehdipals.org)) which is a web-based, interactive resource for finding audiology facilities, parent resources, professional resources, and helpful web sites.

In addition to having birthing facilities conducting newborn hearing screenings and audiologists capable of conducting comprehensive audiologic diagnostic evaluations, knowledgeable PHCPs are important to ensure that the EHDI system works effectively and efficiently to minimize the number of babies who are categorized as LTF/LTD.

The average number of infants who were identified as DHH for 2016-2018 births was 58 and 7 was the average for late onset hearing loss (average age of 449 days from DOB to confirmatory diagnostic evaluation) after passing the initial screen for 2016-2018 births. Late onset or progressive hearing loss occurs for various reasons including acquired illnesses, structural issues, genetic conditions, or injury. At times, the cause of the late onset or progressive hearing loss is unknown or undeterminable.

Currently Early Head Start (EHS) provides early childhood hearing screenings for children up to age 3 in NE, and by year two of the grant period NE-EHDI will determine what other programs in NE provide early childhood hearing screenings for this age group. NE-EHDI will offer to collaborate to assist with the follow-up process to ensure the children who don't pass the hearing screen receive additional screening and/or audiologic diagnostic evaluation and for those identified as DHH to assist in providing information or referral to receive EI services as appropriate.

The population of children and youth with special health care needs (CYSHCN) in NE is especially vulnerable, as they often face confounding challenges and barriers. NE DHHS has partnered to create a network of clinics across the state that provide a range of services for individuals with disabilities. In addition, the partnership has created a system of care for CYSHCN by ensuring that a strong referral network is in place, that services are covered by insurance as much as possible, and by training and supporting parent resource coordinators as family support.

Another component of Nebraska's systems of care involves the shift towards patient-centered medical home practice which has been ongoing in NE for a number of years. A major development in this direction occurred in January 2017 with the creation of Heritage Health, a NE DHHS Division of Medicaid & Long-Term Care approach to administering Medicaid benefits which offers enrollees a single plan combining physical health, behavioral health, and pharmacy benefits in an integrated health care program. The update to this changing landscape is that Medicaid expansion was approved via a ballot measure in the fall of 2018, with the result that up to 90,000 Nebraskans could potentially be eligible for benefits once implemented.

## **METHODOLOGY**

To address the purpose, goal and objectives of the HRSA EHDl grant requirements (stated in the Introduction section of this Narrative), NE-EHDI has established the following goals:

**NE-EHDI Goal 1:** The hearing of all newborns born in Nebraska will be screened during the birth admission or, if born out-of-hospital, by one month of age.

**NE-EHDI Goal 2:** All newborns who "refer" on the initial hearing screening will complete an outpatient re-screening, by one month of age, and/or audiologic diagnostic evaluation by three months of age.

**NE-EHDI Goal 3:** All infants with a confirmed hearing loss will be enrolled in EI services by six months of age.

**NE-EHDI Goal 4:** Early childhood hearing screenings, diagnosis and EI for children up to age 3 will be collected and reported.

**NE-EHDI Goal 5:** An inclusive program will be provided to address the needs of the populations NE-EHDI serves.

**NE-EHDI Goal 6:** Families of young children who are DHH will have access to a family support system to improve family engagement, partnership, and leadership with the EHDl program and systems.

**NE-EHDI Goal 7:** Families of young children who are DHH will have access to a DHH Role Model/Mentor.

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

**A.1. Provide a coordinated infrastructure to:**

- a. Ensure that all newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI by 6 months of age (1-3-6 recommendations); and
- b. Reduce loss to follow-up/loss to documentation.

**Goals 1-7** describe how NE-EHDI will establish and maintain partnerships for referral, training, and information sharing with various state stakeholder organizations and programs currently and by the end of year 1, and will revise annually for Goal 1. This addresses A.3. in the program description activities of the NOFO.

**Goals 1-4** address how NE-EHDI will engage, educate, and train health professionals and service providers in the EHDI system for screening.

**Program Objective and Outcome Measure** - Increase by 10 percent from year 1 baseline the number of health professionals and service providers trained on key aspects of the EHDI Program by March 2024.

**NE-EHDI Goal 1:** The hearing of all newborns born in Nebraska will be screened during the birth admission or, if born out-of-hospital, by one month of age.

**Program Objective (as stated by the NOFO) and Outcome Measure for NE-EHDI:** Increase by 1 percent from baseline per year, or achieve at least a 95 percent screening rate, whichever is less, the number of infants that completed a newborn hearing screen no later than one month of age.

**Goal 1 – Program Activities:** This goal is stated to meet the 1-3-6 Joint Committee on Infant Hearing (JCIH) guidelines and is the first step before diagnosis, referral and EI can occur. Birthing facilities in NE have four primary statutorily-required activities related to screening the hearing of newborns:

1. The parent(s) of newborns are educated about the hearing screening, the likelihood of hearing loss in newborns, the importance of follow-up, community resources (including early intervention services), and normal auditory, speech and language development (Neb. Rev. Stat. §71-4740).
2. A hearing screening is part of each birthing facility's standard of care for newborns, effective 12/1/2002 (Neb. Rev. Stat. §71-4742). Following hospital protocols for the procedure, each newborn's hearing in each ear is screened during birth admission using OAE and/or ABR screening techniques. A second screening is conducted within one to three weeks if the baby "refers" on the first screening.
3. The outpatient re-screening for those that "refer" during birth admission may occur at birthing facility or at a confirmatory testing facility, or by a health care professional.
4. A mechanism for compliance review is established for each birthing facility (Neb. Rev. Stat. §71-4742).

**Goal 1 – Program Monitoring (Reporting, Tracking, and Follow-up):** Since January 1, 2007, the hearing screening results of all occurrent births have been reported to the NE-EHDI Program using the electronic registration system (ERS-II). ERS-II is an integrated module of the State of Nebraska's Vital Records Birth Certificate Registry system. A hearing record (HINFO) is automatically created from the birth certificate by the ERS-II system and populated with baby, mother, and father information, contact information, and demographics (maternal age, race/ethnicity, payment status, maternal marital status, maternal education level). The birth clerk or hearing information clerk at each hospital enters the baby's birth admission hearing screening results (pass, "refer", did not screen) or, if not screened, the reason is selected. Additional information is entered for babies who did not pass ("refer") or were discharged prior to screening: mother's preferred language, telephone number, Primary Health Care Provider (PHCP) name, notification of the



results to PHCP, and follow-up plans to re-screen at the birth facility or to refer to an audiology clinic. Birthing facilities are encouraged to report the hearing screening results within 14 days after birth.

When newborns are transferred to another hospital in the state for a higher level of care, hearing screening results can be entered by the NE-EHDI Program staff or can be entered by the receiving hospital. A one-page reporting form is faxed monthly to each receiving hospital for all babies who have been transferred to that particular facility. For babies who have been transferred to a hospital in another state, the tracking is completed manually by NE-EHDI Program staff since out-of-state staff do not have access to Nebraska's ERS-II Vital Records system.

The NE-EHDI Program sends a letter to the parents and to the PHCP when notification of a failed inpatient hearing screening is received. This letter is followed by a second letter to the PCHP three weeks after the first letter is sent. A second parent letter is sent six weeks after the first letter is sent, and a third letter is sent to the PCHP. This is the 'final request' for follow-up action on the failed screening. NE-EHDI will start utilizing texting for follow-up with parents. This will be implemented by April 1, 2020. The vendor contract with NE DHHS was signed September 2019 and meetings regarding implementation started October 2019.

NE has approximately 100 planned out-of-hospital births reported to the NE-EHDI Program each year. The NE-EHDI Program is required by Neb. Rev. Stat. §71-4740 to educate the parents of babies who are not born in a birth facility about hearing loss, hearing screening, normal speech and hearing development, and resources available. Notification of out-of-hospital births occurs either when the birth certificate is filed in the ERS-II system or when notified by the metabolic/blood spot screening program that a blood spot has been collected, even if a birth certificate has not been filed. The NE-EHDI Program currently mails a certified letter to the parent(s) of a child born out-of-hospital. The educational materials in the parent packet include a brochure about the importance of newborn hearing screening, a URL code to the "Loss and Found" video and a reporting form. Follow-up phone calls are made in an effort to either obtain a formal refusal to have a hearing screening done or the family agrees to obtain a hearing screening for their newborn.

Outreach calls and texts will continue to be made by the NE-EHDI Program Community Health Educator Sr. to the parents with out-of-hospital births who have not completed the newborn hearing screening by one month of age to encourage completion of the hearing screening and assist with any barriers the family may be experiencing.

**Goal 1 – Education and Technical Assistance:** Two basic parent education and follow-up brochures were developed in 2005. Several revisions were completed between 2008 and 2018. The next revision will include information about the importance of having a medical home. The brochures meet the requirements mandated by the Nebraska Infant Hearing Act, are based on the *Universal Hearing Screening Toolkit*, and include suggestions from the NE-EHDI Program Advisory Committee. The brochures, written at a fifth grade health literacy level, have been translated and are available in 14 different languages: English, Spanish, Vietnamese, Russian, Chinese (traditional), Arabic, French, three Sudanese dialects (Dinka, Anuak, and Nuer), Burmese, Nepali, Somali and Karen. The parent education brochures and the English/Spanish videotape *Giving Your Baby a Sound Beginning* and the English/Spanish *Loss and Found* video are disseminated at no cost to birth facilities.

NE-EHDI will continue sending the basic parent education brochure about the importance of newborn hearing screening to birthing facilities, OB/GYNs and PHCPs. The program will encourage the facilities/clinics to place the brochure in waiting rooms, give during prenatal visits and place in prenatal packets given to parents before the baby is born. NE-EHDI will continue to collaborate with Nebraska – Maternal Infant Early Childhood Home Visiting (N-MIECHV) and WIC to give brochures to expectant mothers in their programs. The brochure has been modified to include photographs that better represent the ethnic and racial diversity of families in NE.

Population demographics will continue to be monitored for additional changes. NE-EHDI will be establishing a work group of experts to evaluate during year one whether the program's current procedures, forms, letters, brochures, videos, social media, and website are inclusive of the populations we serve. This will include reviewing Facebook which will be implemented to provide monthly reminders/updates.

A learning community was utilized to develop training for hospital staff to effectively explain hearing screening results to parents to improve rates for audiologic diagnosis and referral to EI by 3 months of age, enrollment in EI by 6 months of age, and family-centered care coordination. The parent leader and NE-EHDI staff researched and evaluated trainings from other state EHDI Programs to assist in writing the draft of the script for a parent perspective video. A script and education cards were drafted in 2017 and revised in 2018. The video was filmed in August 2018 by financially partnering with NE H&V. H&V used funding separate from the funding received by NE-EHDI for the video. Feedback from the learning community, NE-EHDI Advisory Committee and hospital personnel were used to revise the video script and re-film in 2019. The video and education cards are part of a NE Newborn Hearing Hospital Champion Campaign, which is a hospital training that is being piloted during October/November 2019 and then will be finalized to disseminate to all birthing facilities in January 2020.

NE-EHDI will provide educational outreach annually (at a minimum), to inform health professionals that they can find information for parents, birthing facilities, PHCPs, audiologists, early intervention, and family support along with recommended screening and audiologic diagnostic evaluation procedures; links to reports, publications, resources, other appropriate web sites, and NE-EHDI Program contact information at the NE-EHDI Program website ([www.dhhs.ne.gov/publichealth/EHDI](http://www.dhhs.ne.gov/publichealth/EHDI)).

NE-EHDI is partnering with the American Academy of Pediatrics (AAP) NE-EHDI Chapter Champion and a pediatrician from the advisory committee to present to PHCP clinics about the importance of newborn hearing screening, the 1-3-6 recommendations, and their role in the EHDI system based on the AAP guidelines for pediatric medical home providers algorithm. Two laminated handouts are given during the presentation for quick reference regarding the AAP algorithm, risk factors and resources/referral information. The first presentation was in October 2019. More live presentations will be given and recorded so training can be provided statewide.

Individualized technical assistance by telephone and email is provided to birthing facilities, as requested, to address equipment, screening technique, and quality issues. Problems with data entry are resolved by phone, email, or fax. On-site training is offered and provided for new birthing facility personnel with responsibilities for newborn hearing screening and/or ERS-II reporting. Hospital visits and personal phone

calls are also made with those birthing facilities that have high “refer” rates and/or have fallen behind in reporting results.

**Goal 1 – Evaluation and Quality Improvement:** NE-EHDI 2017 CDC HSFS is 97.4% screened by one month of age, of those screened inpatient and/or outpatient. NE-EHDI needs to maintain this goal each year during the four year project period to meet the objective. NE-EHDI always strives to improve even if the goal has been met.

The Infant Hearing Act requires that each birthing facility have a system for compliance review and to report specific aggregate data to the NE-EHDI Program annually. Birthing facilities enter child specific data into the ERS-II for the inpatient hearing screening results or submit the hearing screening files from the screening instrument to a secure NE State website. Some hospitals also manually enter the outpatient screening results into the ERS-II. As of 2018, the NE-EHDI data system records and categorizes the reasons for a delay in the screening, diagnostic or EI enrollment.

NE-EHDI has worked with the largest NE birthing hospital (5,000 births) over the last couple of years to implement the process for their hearing results to be reported from the hospital EHR via an HL7 file that is transmitted to a DHHS server database starting in September 2019. This results in more accurate data with the elimination of over 95% of the manual data entry. Plans are to implement with other large birthing facilities.

Tele-audiology was implemented in 2019 after many years of planning through a committee/learning community comprised of audiologists, parents and deaf educators. This allows infants/children in western NE to have the same access to pediatric audiologists for screenings and diagnostic evaluations as the eastern more populated part of the state. Educational Service Unit (ESU) #13 located in western NE is the site that connects infants/children in Scottsbluff, Chadron and Sidney through tele-audiology to the audiologists at the UNL Barkley Center. It was difficult to find funding for the equipment, our EI Part C partners with the NDE provided funding through a grant to UNL Barkley.

To encourage timely reporting of newborn hearing screening results, the NE-EHDI Business Analyst (BAnalyst) runs an exception report weekly that identifies babies who are older than 14 days of age (excluding those in NICUs) without screening results or without a reason reported for not receiving a hearing screening in ERS-II. A birthing facility is contacted if there are more than two infants without results. Communication with birthing facilities through phone calls and site visits have improved timeliness for reporting inpatient hearing screening results, which is critical for NE-EHDI staff to conduct timely follow-up.

Since babies in the NICU are screened on a developmental basis, rather than by age, the status report is run every three weeks for those babies who are in the NICU and are more than 30 days of age.

Semi-annual status (dashboard) reports for the NE-EHDI advisory committee meetings are created to monitor the follow-up progress of newborns who were “referred”, were discharged prior to screening, or were transferred. The reports include the numbers and percentages in the following categories: closed (child passed a hearing screening), diagnosed (child has a permanent hearing loss), active follow-up, infants without an inpatient screening (e.g., homebirths and discharged without a screening), Loss to

Follow-Up (LFU)/Loss to Documentation (LTD), and expired (died). Timeliness of the initiation of follow-up activities is also included in this report. The status reports have been used for several years and are helpful in monitoring the number and percentages in comparison with the previous years to ensure that the initial follow-up activities are progressing as expected.

The hospital reports available in ERS-II provide a level of analysis of hearing screening outcomes for individual birthing facilities. The analysis includes the number of births at the facility; the number and percentage who passed and didn't pass the inpatient screening; list of reasons not receiving inpatient screening with the number for each reason; number of babies in NICU without results reported; number transferred to another hospital; and number pending data entry results. Each birthing facility has access to ERS-II reports to identify areas for internal quality improvement. In addition, the data system will continue to provide child-specific detailed data reports for hospitals. NE-EHDI also e-mails each hospital a QA summary report annually, which includes the recommended protocols as a friendly reminder.

The Infant Hearing Act requires that an annual report be prepared for Nebraska's Legislature by the NE-EHDI Program. It is an aggregate data report developed from statistical results based on individually-identifiable data submitted by all birthing facilities. The Annual Report provides data on the number of babies as they progress through each component of the NE-EHDI Program system, following the JCIH 1-3-6 recommendations and the type-degree-laterality of all diagnosed hearing loss. The annual report, developed in conjunction with the metabolic (dried blood spot) screening program, is disseminated to all state legislators and the NE-EHDI Program Advisory Committee. Electronic copies are also sent to the CDC and the HRSA Federal Project Officers. The report is also included on the NE-EHDI website.

Communication with hospitals through site visits and phone calls has resulted in an improvement in timeliness for reporting inpatient hearing screening results, and will continue.

**NE-EHDI Goal 2:** All newborns who "refer" on the initial hearing screening will complete an outpatient re-screening, by one month of age, and/or audiologic diagnostic evaluation by three months of age.

**Program Objective (as stated by the NOFO) and Outcome Measure for NE-EHDI:**

- Increase by 10 percent from baseline, or achieve a minimum rate of 85 percent, the number of infants that completed a diagnostic audiologic evaluation no later than 3 months of age.

**Goal 2 – Program Activities:** The audiologic evaluation protocol that was developed and endorsed by the Advisory Committee in 2001 established that, in the interest of reducing costs, the first step in a follow-up hearing evaluation would be an outpatient re-screening using an OAE and/or ABR screening method. This would be done within the first four weeks of age rather than proceeding immediately to diagnostic evaluation. Some local community health systems have opted to have the outpatient rescreening completed at the birthing facility in conjunction with the first well-baby check.

Newborns who have referred on the outpatient hearing screening should receive a diagnostic evaluation prior to reaching three months of age. The purpose of this evaluation is to confirm the presence of a hearing loss, to determine the type and degree of the hearing loss and to recommend medical evaluations and early intervention services.

The NE-EHDI recommended protocols are consistent with the American Speech-Language-Hearing Association (ASHA) revised guidelines for Audiologic Assessment of Children Birth Through 5 years of Age and the Joint Committee on Hearing (JCIH) 2007 Position Statement. The protocols are periodically reviewed to ensure they are consistent with the newest published guidelines.

Successful infant audiologic assessment requires the audiologist to have skills and knowledge to fulfill the roles of diagnostician, counselor, and audiologic case coordinator. The audiologist should discuss the results with the family and report the audiologic results to the infant's PHCP and the NE-EHDI Program. Referrals and recommendations should be made consistent with the JCIH 2007 Position Statement.

NE-EHDI developed an Audiologic Screening and Diagnostic reporting form that parallels the specifications for the hearing audiologic diagnostic (HAUDIO) evaluation module of ERS-II for easier flow of data entry.

**Goal 2 – Program Monitoring (Reporting, Tracking, and Follow-up):** The NE-EHDI Program's tracking and follow-up processes are conducted for each baby reported as not passing the hearing screening during birth admission and for infants not receiving the inpatient hearing screening. In 2018, a total of 1,066 infants (hospital and non-hospital births) were tracked by the NE-EHDI Program to encourage parents to have the infant receive an outpatient hearing screening or diagnostic evaluation. The first step of the NE-EHDI Program tracking procedure is to send an e-fax to the PHCP for newborns who did not pass or were discharged prior to receiving a newborn hearing screening. The PHCP letter is generated within one week of data entry of the hearing screening report into the ERS-II Vital Records system. The letter reports the newborn hearing screening results and requests that the PHCP ensure that the recommended follow-up protocol is completed and the results are reported to the NE-EHDI Program. A letter is also sent to the parent along with a brochure encouraging them to follow-up on the hearing screening and talk to their PHCP. Texting will be another medium used for follow-up with parents by April 1, 2020.

If the results of the outpatient follow-up, either a screening or diagnostic evaluation, have not been received within three weeks, a second request is sent to the PHCP. Three weeks later a third request is sent to the PHCP stating that follow-up has still not been reported to the NE-EHDI Program and a second and final request is sent to the parent at that same time. Contact methods include mail, email, phone, and e-fax. NE-EHDI will connect parents with MHCP if they need financial assistance to schedule an outpatient hearing screen. NE-EHDI will connect parents in western NE who are having difficulty scheduling a timely outpatient hearing screening with tele-audiology at either ESU #13 or UNL Barkley.

The hearing status of some babies is not clearly established with the follow-up outpatient hearing screening or at the first diagnostic evaluation. The status of "Follow-up in Progress" is assigned when additional testing is needed. This category is further divided into those with middle ear dysfunction and an accompanying transient conductive hearing loss and those without any involvement of the middle ear system who will likely go on to be diagnosed with sensorineural hearing loss (SNHL). Tracking becomes more individualized with letters and phone calls by the Community Health Educator/Sr. to the PHCP, which are specific to the nature of the plan, and are based on audiologic and medical recommendations. There are approximately 80 babies in the "Follow-up in Progress" category at any time.

Also, the NE-EHDI staff in 2018 started recording the reason(s) for the delay in the diagnostic evaluation and early intervention events utilizing two new dropdown lists for the primary and secondary reason. This

data helps to identify the reasons for a delay on the confirmation of hearing sensitivity so program improvements can be made if possible and reasons for delay can be reported to the CDC. NE-EHDI requests that audiology clinics report diagnostic evaluations within 5 days of the evaluation date.

In July 2017, the BAnalyst stated exporting hearing data to a spreadsheet to check for duplicate hearing records (involving concatenation of various fields and using an excel formula to check for more than one record with concatenation value in a column).

**Goal 2 – Program Education and Technical Assistance:** The NE-EHDI Program will continue to expand educational opportunities and provide information to professionals and the public about the importance of newborn hearing screening and the EHDI system. For example, the NE-EHDI Team presented on the EHDI system including the 1-3-6 guidelines and the important role of the audiologist to the UNL Auditory Electrophysiology Class in 2019 and will present again in 2020. NE-EHDI presented at the NE Speech Language Hearing Association (NSLHA) in 2017 and 2019; and the NE Nurses Association Conference in 2018. NE-EHDI presents posters annually at the National EHDI Meeting. NE-EHDI provides updates at the DHH Statewide Regional Programs Stakeholder biannual meetings. Not only are deaf educators and other early intervention professionals in attendance at the statewide RPSDHH meetings, but also parents of DHH children, DHH representation, NCDHH, NeAD, BTNRH, H&V/GBYS, neRID, UNL and UNO. BTNRH Audiology, the largest pediatric audiologic diagnostic facility in NE requested NE-EHDI to provide three trainings in October 2018, regarding education about NE-EHDI, timeliness of the diagnostic evaluation, timely reporting of the diagnostic evaluation, and referring to EDN. The American Academy of Pediatrics (AAP) NE-EHDI Chapter Champion provided a brief reminder of the 1-3-6 recommendations and Nebraska’s need to improve the diagnostic evaluations completed by three months of age, as well as providing an infographic handout with the ENT role and resources at the annual NE Otolaryngology Meeting. The NE-EHDI team also provided a booth with additional information about the EHDI system for the ENTs. The program exhibits at several parent and medical professional conferences and health fairs annually. The program will continue to partner with the AAP NE-EHDI Chapter Champion and a pediatrician from the advisory committee to educate PHCPs and ENTs.

**Goal 2 – Program Evaluation and Quality Improvement:** NE-EHDI 2017 CDC HSFS is 62.9% for diagnosis at 3 months. For NE-EHDI to meet this objective by the end of the year four project period, we will need to increase to 69.2%.

Letters to the PHCP include recommended follow-up protocols for birth admission and outpatient hearing screenings with “refer” results and for audiologic evaluations indicating a permanent hearing loss. The protocols have been refined over the last few years to more clearly represent the current JCIH guidelines and to more accurately reflect changes in the EHDI follow-up system.

The EHDI follow-up process for families and offering H&V/GBYS family support is streamlined by H&V/GBYS assisting EHDI with follow-up for families and medical professionals, as well as providing education and family support. This gives families an opportunity to be involved with GBYS for family support sooner and to connect with a GBYS Parent Guide with their first EHDI contact. The Guides are available to respond to the individual needs of each family to assist families in helping their child reach their full potential.

NE-EHDI received a list of the audiologists from NE DHHS Licensure in 2018. NE-EHDI surveyed the audiologists in NE who see pediatric patients to find out their level of understanding regarding what EHDI does; the importance of timely diagnostic evaluations and timely reporting of diagnostic evaluations; how to report results of the hearing screenings and diagnostic evaluations to NE-EHDI; providing education to parents about next steps once their child is identified as DHH; importance of timely referral to EI; and how to refer to EI. NE-EHDI developed the survey with input of the NE-EHDI team and with information received from other EHDI programs.

NE-EHDI evaluated and analyzed the survey data; shared the data with the NE-EHDI Advisory Committee to receive feedback and ideas for questions for the audiology clinic meetings; and then scheduled in person meetings with the five main pediatric audiology clinics in NE. It was determined that all audiologists who see pediatric patients in NE are reporting results to NE-EHDI by either 1) completing the online fillable Audiologic Screening and Diagnostic Report Form, then faxing to the NE-EHDI secure electronic fax where NE-EHDI staff enter the information into the ERS-II, or 2) directly entering into the ERS-II. There are five main pediatric audiology clinics that provide approximately 95% of the infant pediatric hearing evaluations in the state. The remainder of the clinics only see a few infant pediatric patients periodically. Some of these audiologists see very few infants.

The key finding from the survey data determined that the five main pediatric audiology clinics do not have any barriers for reporting, but the audiology clinics who do not see pediatric patients very often do not remember or are not familiar with the steps for reporting results. Another barrier discovered is that some of the audiology clinics are short staffed so there are times that it is difficult to report timely. Lessons learned from meeting with audiologists: 1) There are always new audiologists starting so NE-EHDI needs to communicate with audiologists on a regular basis regarding information about EHDI and reporting to EHDI; 2) There is only one audiologist west of Lincoln, NE who is a pediatric audiologist. Another reason for the shortage of audiologists who see pediatric patients is due to them not taking Medicaid patients; and 3) Audiologists would be more apt to complete trainings if CEUs are offered.

The following changes were implemented after the meetings – revised the NE-EHDI Audiologic Screening and Diagnostic Report form; revised the Audiologists page and Families page on the NE-EHDI website; developed a NE-EHDI Summary and Reporting Guidelines for Audiologists document (this includes the importance of providing current and accurate information to families, including decisions about the full range of assistive technologies and communication modalities); and developed a list of birthing facilities who use ABR or OAE for screening. NE-EHDI partnered with audiologists and utilized Joint Committee on Infant Hearing (JCIH) recommendations to develop a risk factor document, which was e-mailed to birthing facilities with the link to the CDC risk factors poster. The risk factor document and CDC risk factor poster were also mailed to PHCPs statewide. NE-EHDI e-mailed audiologists September 2018 to inform them of all the updates made and the new forms that NE-EHDI developed based on the feedback from NE Audiologists. This was the first e-mail of the new series of biannual e-mails to provide updates and reminders to audiologists about the 1-3-6 guidelines, reporting procedures to EHDI, and to ask for program improvement feedback. NE-EHDI offered to provide in-service trainings for new audiologists and as a refresher for experienced audiologists. NE-EHDI provided three trainings to the BTNRH Audiologists October 2018. NE-EHDI met/trained with Children's Hospital Audiologists February 2019. NE-EHDI developed an Audiology QA report that was finalized with the input of the audiologists and the first annual Audiology QA reports were e-mailed May 2019.

As detailed in Goal 1 – Program Evaluation and Quality Improvement, this measure is included in the semi-annual status reports reviewed by the Advisory Committee and in the Annual Report submitted to the Legislature.

The CDC collects aggregate data from state EHDI programs through the CDC EHDI HSFS. The HSFS report is completed and submitted annually along with other national surveys as requested.

Ad hoc reports are utilized to gain a more in-depth understanding of the progress of babies from one phase in the recommended protocol to the next in the EHDI system regarding the JCIH 1-3-6 guidelines. Analysis of various maternal demographics will be continued for those with untimely rescreening and diagnosis as well as efforts to identify the birthing facilities and PHCP practices providing care for the families.

The Community Health Educators, along with the contracted H&V/GBYS Guide will continue to be active in follow-up by phone to the PHCP and parents at the first sign of system failure, such as a PHCP being incorrectly identified or the parent not following through with recommended follow-up. The H&V/GBYS Guide will make reminder appointment phone calls to the parents and provide directions to the audiologist's office if needed.

The NE-EHDI Program will continue to use a form which is faxed to the PHCP to obtain outpatient hearing results. The PHCP can fax the form back when results are received from the hearing screening facility or audiologist. The one-page audiologic reporting form that parallels the HAUDIO (Hearing Audiologic Diagnostic) module for ERS-II will continue to be utilized.

The HAUDIO module of ERS-II which permits audiologists to report results of screening, diagnostic evaluations, and recommendations became available after beta testing in 2010. This module was developed with funding from the CDC cooperative agreement. NE-EHDI has Business Associates Agreements (BAAs) with three of the largest pediatric audiology clinics in NE who enter diagnostic results directly into ERS-II. This process is more efficient for reporting and less data entry for NE-EHDI. These three audiology clinics provide about 86% of the diagnostic evaluation services for infants in NE (age three and younger). Other audiology clinics fax results to a secure e-fax for NE-EHDI staff to enter results.

NE-EHDI developed a quarterly report in 2018 that lists diagnostic (Dx) cases where the Dx report is received more than 7 days from the Dx appointment date. This report allows NE-EHDI to target clinics who have delays in reporting diagnostic data so NE-EHDI can discuss with them the reason why and help resolve the issue(s). Overall, the diagnostic facilities report timely to NE-EHDI. The NE-EHDI BA audits/reviews diagnostic data and compares the data entry to the narrative evaluations received from audiologists.

The NE-EHDI BAnalyst completed a Statistical Analysis Software (SAS) course in June 2018, and then started utilizing SAS to identify duplicate hearing (HINFO) records - based on medical record number (MRN). SAS is also utilized to maintain a 1-to-1 correspondence between the birth table and the HINFO table (i.e. find missing HINFO records). This process is much more efficient and is used on-going.



As detailed in Goal 1 – Program Evaluation and Quality Improvement, the availability of tele-audiology allows infants/children in western NE to have the same access to pediatric audiologists for screenings and diagnostic evaluations as the eastern more populated part of the state. This also assists with scheduling more timely diagnostic evaluations.

**NE-EHDI Goal 3:** All infants with a confirmed hearing loss will be enrolled in EI services by six months of age.

**Program Objective (as stated by the NOFO) and Outcome Measure for NE-EHDI:** Increase by 15 percent from baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.

**Goal 3 – Program Activities:** The processes used by NE-EHDI to collect, analyze, and report data to meet the JCIH guidelines were described in Goals 1 and 2.

Various services are available for children identified as DHH in NE. EDN, the Part C EI in NE, is one of the main services. NE-EHDI 2017 HSFS data for those infants identified as DHH who were born and reside in NE shows 75% were enrolled in EDN/Part C. EDN/Part C helps families support and promote child development within family activities and community life. There are 29 Early Childhood Planning Region Teams. Each one has an Interagency Coordinating Council made up of schools, health and human service agencies, Head Start, families, and others. Anyone can make a referral directly to EDN.

Another service for NE families is the MHCP that is part of the CYSHCN Program. This program, under the NE DHHS, offers coordination/case management, access to specialty physicians, and payment of treatment for services.

There is also a family support network available to families of young children identified as DHH that was described in the Introduction of the Narrative.

Early intervention partners have developed a process for parents of very young children recently identified as DHH to have a recognized coordinated initial point of entry into the early intervention system. The organizational partners for the plan included the EDN/Part C, RPSDHH, PTI-NE, MHCP, Hands and Voices, and the NE-EHDI Program who identified EDN/Part C as the initial point of entry.

Another large piece of providing support for the referral process is the NE-EHDI partnership with NE H&V/GBYS to conduct follow-up and assist families with EI and family-centered care coordination. More details are explained in Goal 6 regarding this agreement.

NE has a statewide hearing aid loaner bank, a partnership between NE-EHDI and the audiology program at the University of Nebraska-Lincoln (UNL) dating back to 2008. It is now known as HearU NE. As of July 2019, 440 children have received one or more hearing aids for a total of 738 hearing aids being fitted since 2008. Hearing aids are loaned for a period of five years, with extensions as needed. Inventory includes new and recently refurbished hearing aids. Children must be referred by an audiologist and parents complete an application for the hearing aids. In most cases the hearing aids are loaned and then returned to HearU NE to be used again.

**Goal 3 – Program Monitoring (Reporting, Tracking, and Follow-up):** The NE-EHDI BAnalyst accesses the NE CONNECT data system at least monthly to check the EDN/Part C referrals and verifications are completed for infants who have been reported as DHH. EDN data include the referral date, verification date, individual family service plan (IFSP) date, primary disability category, services coordinator, case status (active or closed) as well as other details. The EDN information for each child is then recorded in the ERS-II hearing information database table. One challenge of the CONNECT system is that only the primary verified disability is listed. Children who are DHH, and also have other disabilities may be categorized in the CONNECT system according to a disability other than DHH. EDN started providing a quarterly report in 2018 that has a listing of infants enrolled in EDN with the primary verification of a hearing loss (with name and DOB). The NE-EHDI BAnalyst reviews the EDN quarterly reports to ensure NE-EHDI data and EDN-CONNECT data matches for every child identified as DHH and referred/enrolled in EI. NE-EHDI continues to meet annually with EDN, and during NE-EHDI biannual advisory meetings if needed regarding improving the capture and timeliness of EI data for infants.

**Goal 3 – Program Education and Technical Assistance:** When an infant is identified as DHH and reported to the NE-EHDI Program, the parent(s) receive the Parent Resource Guide (PRG) from the audiologist and a notification letter is sent to the PHCP. Materials in the PRG include information about communication options, questions to ask the audiologist and other professionals, and the Funding Toolkit that is updated as needed by the RPSDHH. A guide to family support services that was developed through a collaboration of a graduate student in deaf education and the NE H&V is also included. A “roadmap” of services and the sequencing of those services was developed during the NICHQ Learning Collaborative, based on a template provided to the participants. NE-EHDI added an electronic version of the PRG to our website so parents will have the option of a packet or online access.

Outreach to audiologists and PHCPs by EDN’s Planning Regional Teams (Local Interagency Coordinating Councils) to educate primary referral sources about the importance of early intervention and the mechanism to refer for services will continue. EDN contact information is included in the education brochure to parents about the hearing screening and the “refer” brochure, as well as the Loss and Found video that has been developed and is disseminated by the NE-EHDI Program. Letters to the PHCPs and the recommended follow-up protocol, presented in the PHCP algorithm, include information and encourage the EDN referral.

As mentioned in Goal 2, NE-EHDI developed a “Summary and Reporting Guidelines for Audiologists” document after surveying and meeting with audiologists in 2018. Information in this document includes the referral steps to EDN for EI in NE. The steps for referring to EDN are also on the NE-EHDI website. EDN presented about their program at the NE-EHDI Advisory Meeting in November 2018. As mentioned in Goal 2, the NE-EHDI TEAM presented to the UNL Auditory Electrophysiology Class in 2019 and will present again in 2020. The importance of audiologists referring to EDN for EI was discussed during the presentation.

**Goal 3 – Program Evaluation and Quality Improvement:** NE-EHDI 2017 CDC HSFS is 78.9% for timely enrollment to EI at 6 months. For NE-EHDI to meet this objective by the end of the year four project period, we will need to increase by 1.1% to 80%. NE-EHDI always strives to improve even if the goal has been met.

The NE-EHDI Annual Report, required to be prepared for the NE Legislature, includes information about the numbers and percentages of infants identified as DHH and enrolled in EI (EDN)/Part C. EI data is also reported as part of the annual CDC HSFS report.

Audiologists provide the Parent Resource Guide (PRG) to parents when a child under age 3 is diagnosed with permanent hearing loss. All have expressed positive experiences and will continue providing this resource to families. Feedback and content of the PRG is continuously being evaluated and revised. The content has been organized in a more logical manner and the sections are broken down into “steps” to help parents understand what to do next. In addition, a User Manual was designed to be used along with the PRG, so parents know where to find certain topics that may be of interest to them. Some families have commented that due to the emotions some parents feel at the time of identification, they may be so overwhelmed that they won't open the PRG right away. A new brochure that addresses the emotional impact of having a child identified as DHH was written to be given to the parents at the time the PRG is provided. The Experience of Care Parent Survey is included in the PRG. A URL code to the survey is in the NE-EHDI “Can Your Baby Hear?” brochure that birthing facilities give to parents and the survey is also provided on the NE-EHDI website on the Parents page.

The NE-EHDI Program Analyst will continue to access the CONNECT data system to verify that each child diagnosed as DHH is referred to EDN/Part C and verify that the EDN details are recorded in the ERS-II hearing information database table. NE-EHDI received approval from EDN that a referral can be made to EDN after a baby is 4 months of age and has not yet been diagnosed, but has a transient hearing loss that may cause delays in speech and language development. A referral can't be made to EDN for non-compliant parents since it doesn't meet EDN's state and federal requirements for an early intervention referral.

NE-EHDI will continue to have an agreement with the NE H&V/GBYS Program and HearU NE that is discussed more in Goal 6.

**Loss to follow-up/loss to documentation (LTF/LTD):** When all follow-up requests have been exhausted (mail, telephone, contact with the PHCP, etc.) a final letter with the URL code to the Loss and Found video is sent to the parents. The letter includes information on the impact of undetected hearing loss on a child's speech, language, and social-emotional development. If there has not been any two way communication between the EHDI staff and the parents, or the PHCP and the parents, the case is marked LTF/LTD. If two way communication has occurred and been documented, and the parents have not complied with the follow-up protocol, the case is marked unresponsive. NE-EHDI has improved greatly on the LTF/LTD over the years. There were 193 infants in the lost status and unresponsive status in 2010 and 26 infants in 2017. The reduction in key staff turnover was a major factor in reducing LTF/LTD in NE. The same person has been the Follow-up Coordinator since 2011. Many times a case is lost because the parent's contact information was not provided to EHDI by the hospital, or the family has moved or changed phone numbers, and/or the PHCP information is missing or incorrect. NE-EHDI uses a number of different databases and resources to find current contact information. Resources include NE Medicaid database, NE Economic Assistance database, NE Health Information Initiative (NeHII), Perkin Elmer Genetics Dried Blood Spot database, contacts with NE Child & Family Services, EDN, connection with other states within the EHDI system, and looking for information on social media like Facebook. Frequent outreach from NE-EHDI to both parents and PHCPs is a key component of reducing LTF/LTD. Parent education and parent

engagement in the EHDl process are necessary for successful outcomes. NE-EHDl continues to educate parents, health professionals, early intervention professionals and family support professionals about the importance of the 1-3-6 guidelines so children can stay on track academically with their hearing peers and achieve on time social and emotional milestones to have the opportunity to reach their full potential. NE-EHDl plans to implement Facebook to provide monthly reminders/updates. As mentioned in the previous goals 1-3 program evaluation and quality improvements include many procedures and reports which not only assist in meeting the 1-3-6 guidelines timely, but also reduces LTF/LTD.

**A.2. Develop a state/territory plan to expand infrastructure, including data collection and reporting, for hearing screening for children up to age 3 by the end of year 2.**

**NE-EHDl Goal 4:** Early childhood hearing screenings, diagnosis and EI for children up to age 3 will be collected and reported.

**Program Objective (as stated by the NOFO) and Outcome Measure for NE-EHDl:**

Have a plan in place for data collection and reporting early childhood hearing screening, including diagnosis and EI for children up to age 3 by the end of year 2.

**Goal 4 – Program Activities:** The NE-EHDl Program was an early adopter of the National Center for Hearing Assessment and Management’s (NCHAM) Early Childhood Hearing Outreach (ECHO) Initiative’s work with training EHS programs to conduct OAE screenings. Six NE EHS programs were trained, all of which have continued implementation of OAE screening. One program submitted hearing screening results to NE-EHDl from the screening instrument to a secure NE State website (a web-based drop box) quarterly from 2013-2015. The goal was to have the other EHS programs submit data through the same process. This collaboration work was put on hold when the NE-EHDl Coordinator retired in June 2016. After the new NE-EHDl Coordinator started, the focus of the EHDl work shifted to meet the new HRSA 2017-2020 funding requirements. This resulted in the EHS collaboration work continuing to be on hold. Once the NOFO for the 2020-2024 HRSA funding was released, the NE-EHDl Coordinator started discussing collaboration again with the NE Head Start State Collaboration Office Director (NE HSSCOD) and the NE Head Start Association (NeHSA). The NE-EHDl Program plans to partner again with EHS for hearing screenings and expand to collect data regarding the early childhood hearing diagnostic evaluations and EI for children up to age 3. All the NE EHS programs conduct OAE screenings within 45 days of the child being enrolled in the program. In fiscal year 2018, there were 1,609 children enrolled in EHS programs in NE. More details about the partnerships will take place in 2020. The NE-EHDl Coordinator will meet with the NE HSSCOD and the NeHSA Chair in early 2020. The NE-EHDl Coordinator is scheduled to attend and present at the NeHSA board meeting April 2020 to discuss more about our collaboration.

A plan will be developed to improve coordination of care and services for families and children who are DHH for formal communication, training, referrals, and/or data sharing with NE-EHDl and early childhood programs. This will include establishing agreements with the EHS programs and possibly other early childhood programs. Through the agreements, NE-EHDl will ask the early childhood programs to provide strategies that follow the ECHO screening protocol and submit individually-identifiable hearing screening and diagnostic information quarterly. This may identify some young children who have been categorized as LTF/LTD, as well as identify those with later-onset hearing loss who could benefit from additional EI and family support services. The details of the agreements will be determined in 2020.

**Goal 4 – Program Monitoring (Reporting, Tracking, and Follow-up):** Monitoring the late-onset or progressive hearing loss through early childhood hearing screenings, diagnostic evaluations, referring to EI as appropriate, and connecting with family-to-family support and DHH adult consumer-to-family support will be added to the NE-EHDI protocol. NE-EHDI will provide follow-up with the parents, PHCPs, audiologists, and EI for children who don't pass (refer) the early childhood hearing screening to assist with children receiving timely diagnostic, EI (EDN), family, and DHH support as appropriate. As stated later in the Organizational Information section, NE-EHDI has a small staff and will need to monitor through analysis and planning if there are enough current resources for the same level of follow-up for the early childhood hearing screenings who refer and need diagnostic evaluation as exist for the newborn hearing screenings. If it is determined that there aren't enough resources, NE-EHDI will either modify the early childhood follow-up process, or seek more financial support from Title V and possibly request for another follow-up position.

The NE-EHDI BAnalyst will expand the NE-EHDI ERS-II to report and track early childhood hearing screens up to age 3. Fields will be developed in ERS-II with names of programs/agencies providing early childhood hearing screens for children up to age 3 and fields for tracking results and follow-up for hearing screenings, diagnostic evaluations, EI, and receiving family support information. Reporting protocols, tracking and follow-up through letters, phone calls and texting of refers for hearing screening, diagnostic evaluations, EI, and family support will be developed similar to Goals 1-3 for this age group.

**Goal 4 – Program Education and Technical Assistance:** NE-EHDI will connect early childhood programs with the ECHO Initiative for training/technical assistance about hearing screening protocols, and assist with the PHCPs to refer to audiologists for timely diagnostic evaluations and referring to EI as appropriate. NE-EHDI will provide education and resources about the importance of early childhood hearing screens, diagnostic, and EI for children up to age 3 for early childhood programs, daycares, N-MIECHV, WIC and parents. NE-EHDI will partner with HRSA's FL3 Center, NTRC, and NCHAM ECHO Initiative for resources, technical assistance, training, education, QI, and evaluation. The program will gather existing educational materials and modify as needed for NE. Information about early childhood hearing screens will be added to the NE-EHDI website and included in presentations and information shared at exhibits for conferences and health fairs. NE-EHDI will be establishing a work group of experts to evaluate during year one to determine if the program's current procedures, forms, letters, educational information and website is inclusive of the populations served.

**Goal 4 – Program Evaluation and Quality Improvement:** Protocols will be established and monitored with changes made as needed. Ad hoc reports will be created to monitor follow-up for timely diagnostic evaluations and referrals to EI. As with newborn hearing screenings follow-up, H&V/GBYS will assist with EHDI follow-up for families and medical professionals, as well as providing education and connecting with family support. Visits and/or phone calls will be made with early childhood programs who have high "refer" rates and/or have fallen behind in reporting results. The early childhood reporting will be added to the semi-annual status reports for the NE-EHDI Advisory Committee meetings. The early childhood information will also be added to the annual NE Legislature Report.

**NE-EHDI will report QI annually to monitor and assess program performance in meeting the stated program purpose and objectives that would contribute toward continuous quality improvement (QI)**

**throughout the period of performance for expansion of screening, diagnosis, EI, and family support up to age 3.**

- PDSA year 1 - Improve coordination of care and services for families and children who are DHH between the NE-EHDI Program and early childhood programs by identifying early childhood programs who conduct hearing screenings, the training their staff has completed for conducting OAE hearing screens, and their interest in partnering with NE-EHDI regarding referrals for diagnostic evaluation, EI, family support, and data sharing.
- PDSA year 2 - Develop a plan for data collection and reporting early childhood hearing screening, including diagnosis and EI status for children up to age 3.
- PDSA year 3 - Document formal communication and training that is provided and show the evidence of success by the number of referrals and/or data sharing provided by the number of agencies sharing data.
- PDSA year 4 – Evaluate once implemented and identify areas for improvement, and establish new PDSA.

**A.3. Establish and maintain partnerships for referral, training, and information sharing with various state or territory stakeholder organizations and programs.**

- The many stakeholders who partner with NE-EHDI are essential to have a successful EHDI system and are discussed throughout Goals 1-7 in the narrative.
- NE-EHDI will report to HRSA by the end of year 1 all the current and new stakeholders the program worked with during this time and will revise the list annually.

**A.4. Multidisciplinary Program Advisory Committee:** In addition to the NE-EHDI Program's multidisciplinary program advisory committee described in the introduction (page 4) members include representation of Audiology; Pediatrician, Early Intervention Services - NDE – EDN, Planning Region Team – Special Education and Communications Disorders, and RPSDHH; Otolaryngology; Family Support Organizations – PTI NE, H&V/GBYS; Hospital OB Director; University of Nebraska-Omaha Social Work Program; NCDHH; NeAD; and NE Newborn Bloodspot Screening. Each member is requested to serve a term of two years but may continue to serve at their discretion for longer periods, unless their absence at meetings exceeds attendance. The Chair, and in the absence of the Chair, the Vice-Chair are responsible for the following:

- Leading the Advisory Committee meetings with the NE-EHDI Program Manager.
- Approval of meeting agendas and minutes.
- Represent the Advisory Committee as appropriate.
- Chair may call a meeting of the Advisory Committee at their discretion.

The Advisory Committee will generally make its recommendations by consensus. In the event that consensus cannot be reached within a reasonable timeframe, there will be a majority rule.

The NE-EHDI Program was created based on the requirements identified in the Nebraska Infant Hearing Act of 2000 and the recommendations of the NE-EHDI Program Advisory Committee.

In June 2011 the NE-EHDI Program Advisory Committee approved the mission statement that was included in the Introduction section of the Narrative.

The purpose of the NE-EHDI Advisory Committee is to provide direction and guidance to the NE-EHDI Program regarding the newborn hearing screening system. Specific Advisory Committee activities include, but are not limited to, the following:

- To discuss and advise on the goals for the NE-EHDI Program.
- To advise on the improvement of reporting, tracking, and follow-up protocols to effectively link the NE-EHDI Program and early intervention systems.
- To assist in increasing the program's responsiveness to the expanding cultural and linguistic communities in the state.
- To guide the long-term planning and evaluation of the NE-EHDI system in the state.
- To review the quarterly newborn screening statistics and make recommendations for program improvements.

**A.5.** Address diversity and inclusion in the EHDI system to ensure that the state or territory's EHDI system activities are inclusive of and address the needs of the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.

**NE-EHDI Goal 5:** An inclusive program will be provided to address the needs of the populations NE-EHDI serves.

**Program Objective (as stated by the NOFO) and Outcome Measure for NE-EHDI:**

By the end of year 2, develop a plan to address diversity and inclusion in the EHDI system to ensure that the state's EHDI system activities are inclusive of and address the needs of the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.

**Goal 5 – Program Activities:** The NE-EHDI team continuously strives for the EHDI system to be inclusive for the collaboration partners and the population we serve. The May 2018 NE-EHDI Advisory Meeting and feedback were evaluated to reflect on how to improve the advisory meeting environment so it is a place of respect for ALL members. It has been difficult for some of the DHH members and other members to agree on terminology to be used during the NE-EHDI advisory meetings. Since repetitive, lengthy, and sometimes hurtful comments continue to happen at advisory meetings, a work group addressed this issue after the May 2018 meeting. A position statement was developed and approved by the advisory committee to be read at the beginning of each advisory meeting to remind everyone to focus on the NE-EHDI mission statement and to be respectful of each other. It is important for members to feel comfortable asking questions and providing information during the meeting so we can continually improve the EHDI system.

During the new funding period, NE-EHDI will make a list of all procedures, forms, letters, brochures, videos, social media, and website to evaluate. A work group will be established to evaluate each item NE-EHDI has identified to ensure information and procedures are inclusive for geography, race, ethnicity, disability, gender, sexual orientation, family structure, and socio-economic status for the populations we serve. Work group members will be invited from NE DHHS Office of Health Disparities; NE DHHS Community and Rural Health Planning; Outlinc (organization that works with LGBT+ across the state; PTI-NE; NCDHH; NeAD; DHH individuals; audiologists; EDN; deaf educators and others that may be suggested by the work group. After all the information has been assessed then a plan for improvement will be developed. NE-EHDI staff will write the draft plan based on the feedback from the work group. NE-EHDI will present the draft plan to the work group to review and revise. The plan will be finalized by 3/31/2022.

**Goal 5 – Program Monitoring (Reporting, Tracking, and Follow-up):** NE-EHDI will monitor throughout the year and make changes when feedback is received. Any new procedures and new education will be assessed to meet the criteria/plan developed.

**Goal 5 – Program Education and Technical Assistance:** The all-inclusive format will be included in all procedures, meetings and education through brochures, infographic documents, presentations, exhibits, social media, videos, website, and resources that are stated in Goals 1-4 and 6-7. The all-inclusive format will be discussed at the biannual advisory meetings.

**Goal 5 – Program Evaluation and Quality Improvement:** A survey will be developed and placed on our website asking for feedback regarding if any of our information needs to be changed to ensure our program is being inclusive to meet the needs of all the populations we serve. We will ask the advisory committee for feedback at the biannual meetings and encourage them to complete the online survey if they identify changes that should be made. The NE-EHDI team will annually assess all the procedures and education provided to ensure everything is meeting the criteria/plan developed.

**A.6. Develop and implement a strategy to monitor and assess program performance in meeting the stated program purpose and objectives that would contribute toward continuous quality improvement (QI) throughout the period of performance.**

1. NE-EHDI will provide QI throughout the four year performance period for expansion of screening up to age 3. Details are stated in Goal 4 – Program Evaluation and Quality Improvement. A QI report will be written and submitted annually to HRSA.
2. NE-EHDI will provide QI throughout the four year performance period for family engagement and family support, including the implementation of the DHH Role Model/Mentor Program. A QI report will be written and submitted annually to HRSA.

**H&V/GBYS Program** – The H&V/GBYS Coordinator will track the number of families enrolled in family-to-family support by 6 months of age and those not interested in the support by 6 months of age. It will be documented if a reason is given why the family is not interested by 6 months of age. The H&V/GBYS Coordinator will also track if the family enrolls at a later time. Changes will be made with the GBYS Program if possible from the parents' comments and suggestions. Feedback is requested annually about support from GBYS Guides and feedback is received after every family support event to change or expand events to meet the needs.

**DHH Role Model/Mentor Program – PDSA year 1** - Gathering feedback from parents, establishing a work group and the work group starts to meet. The NE-EHDI team and external partners will draft a survey and interview questions to find out the needs and wants of families for a DHH Role Model/Mentor Program in NE. The NE-EHDI Advisory Committee will be asked to review the survey and interview questions. Changes will be made from their suggestions to finalize the survey. The survey will be sent out to all families enrolled in the H&V/GBYS Guide program. Parent Guides will also discuss the interview questions when meeting in person with families. The State Liaison for Programs for Children who are DHH with the NDE stated the deaf educators across the state would send the survey to families or interview the families they serve as well. If other avenues are discovered for how to receive parent feedback they will also be used during this time.



NE-EHDI will invite parents, DHH individuals, H&V/GBYS, PTI-NE, NCDHH, NeAD, deaf educators, EDN, audiologists, PHCPs, and any others interested to serve on a work group to take the feedback from parents statewide and discuss what the structure for the DHH Role Model/Mentor program in NE should be, what agency/organization will be the home and management of the program, number of role models/mentors needed to provide an opportunity for families to meet and learn about the wide range of communication modalities used, training for the role models/mentors, promotion, evaluation, and financial support for implementation and sustaining of the program.

**PDSA year 2** – The work group will meet every other month to determine the structure of the DHH Role Model/Program, training, organization/agency providing the home for the program, financial support to implement and sustain as stated in PDSA 1. NE-EHDI will partner with HRSA’s FL3 Center and NTRC for resources, technical assistance, training, education, and QI throughout the four years. Work group members will be asked for input regarding the process to develop a DHH Role/Model Program and adjustments will be made accordingly.

**PDSA year 3** – The goal is for the agency/organization who will be the home and management of the program to be selected during the first quarter of year 3 so a contract/sub-award can be started with NE-EHDI. Planning of the program will include developing and implementing protocols, determining the number of staff to hire, and completing staff training that is decided as appropriate by the work group. Promoting and educating about the DHH Role Model/Mentor Program will occur during the fourth quarter of year 3 and throughout year 4. As these steps are developed and implemented, they will be reviewed and changes made through a PDSA cycle. Implementing the program will take place at the end of year 3.

**PDSA year 4** – Continue implementation and make changes from participant feedback and from feedback of those managing the program. The DHH Role Model/Mentor Program will provide quarterly reports to NE-EHDI of the total number of families enrolled in the program and track separately the number of families enrolled in the program by the time the child who is DHH is 9 months of age. Documentation will include the reason the family doesn’t want to be enrolled in the program by 9 months of age if the family declines the program, as well as the date and age of the child if the family enrolls in the program after 9 months of age. Reports will include the percent increased by baseline of the number of families enrolled in the program by March 2024. As the program is implemented, the many procedures will be reviewed and changes made through a PDSA cycle.

**A.7. Develop, maintain, and promote a website or webpage:** NE-EHDI has a website with a wealth of information and resources for parents, PHCPs, hospitals, audiologists and the public to learn more about the EHDI system. The NE DHHS website including the NE-EHDI website was revised in 2019 to be more user friendly as well as mobile friendly. The website is reviewed on-going and revised as needed to better inform parents and professionals about the importance of the EHDI system and to show all the partners involved a successful EHDI system. NE-EHDI provides educational outreach annually (at a minimum), to inform health professionals that they can find information for parents, birthing facilities, PHCPs, and audiologists; recommended screening and audiologic diagnostic evaluation procedures; links to reports, publications, resources, other appropriate web sites, and NE-EHDI Program contact information at the NE-Nebraska Early Hearing Detection and Intervention Program

Competing Continuation H61MC00065

HRSA-20-047 (Period of Performance – April 1, 2020 – March 31, 2024)

EHDI Program website ([www.dhhs.ne.gov/publichealth/EHDI](http://www.dhhs.ne.gov/publichealth/EHDI)). This is achieved through mailings, e-mails, and presentations and exhibits at conferences, meetings and health fairs.

**A.8. Sustainability:** The NE-EHDI Advisory Committee has discussed potential sources of funds in addition to the HRSA EHDI federal grant and the CDC EHDI cooperative agreement funds. Research discovered that a few EHDI programs receive a fee from newborn blood spot screening to help fund their program. The current NE legislation for blood spot screening doesn't allow the fee received by the program to be shared with EHDI. NE-EHDI discussed with the advisory committee regarding their interest to pursue a legislative proposal to NE DHHS after Colorado passed legislation in 2018 to receive a \$4/baby fee for the hearing screening (separate from the blood spot screening). The advisory committee approved pursuing a legislative proposal and NE-EHDI submitted a proposal July, 2019. While it had initial internal support, it did not make the final cut among many legislative bill proposals submitted. The HRSA Maternal Child Health (MCH) Title V Block Grant has enough funds to help support EHDI over the next few years. NE DHHS suggested utilizing these funds for additional support at this time. NE-EHDI is currently utilizing HRSA MCH Title V funds to sustain the program since HRSA EHDI and CDC EHDI funds are not enough to cover the basic operations of the program.

EDN provides some funding for the GBYS program. The RPSDHH have provided financial support for BTNRH Roots and Wings/Parent Training workshops and other H&V/GBYS and NE-EHDI family support events. HearU NE receives additional funding through a variety of foundations and fund raising events.

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

**B.1. and B.2.** Are addressed in Goals 1-4.

**Program Objective and Outcome Measure** - Increase by 10 percent from year 1 baseline the number of health professionals and service providers trained on key aspects of the EHDI Program by March 2024.

NE-EHDI will document the number of health professionals and service providers trained on key aspects of the EHDI Program at the end of year one. NE-EHDI will plan annually with the advisory committee by identifying new professionals and service providers to be trained to meet this objective by March 2024.

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

**NE-EHDI Goal 6:** Families of young children identified as deaf or hard of hearing will have access and will be encouraged to engage with a family support system.

**Program Objective (as stated by the NOFO) and Outcome Measure for NE-EHDI:**

Increase by 20 percent from year 1 baseline the number of families enrolled in family-to-family support services by no later than 6 months of age.

**Goal 6 – Program Activities:** The following activities will explain how NE-EHDI will partner and provide 25% of the budget to family support organizations and/or organizations that support families for children who are DHH. NE-EHDI has had contracts/sub-awards with H&V/GBYS, HearU and BTNRH for family support for several years and will continue throughout this four year grant period.

The NE H&V was organized in 2006 with financial assistance from the NE-EHDI Program. The NE Chapter was officially formed in 2007 and became a 501(c) (3) not-for-profit organization in 2010. In 2013, the Chapter received approval from the National GBYS Program to establish a NE GBYS Program. A part-time coordinator was hired and parent guides were recruited and trained. The H&V/GBYS program also receives funds from EDN/Part C. There are currently 14 trained Parent Guides throughout the state. As stated in Goals 1-3, starting with a contract in 2017 the H&V/GBYS Coordinator assists with EHDI follow-up and provides assistance to families for EI, care coordination, and connecting families to family support. The H&V/GBYS Coordinator followed-up with 1,916 families in the EHDI system from 5/1/17 – 10/1/2019. NE-EHDI and H&V/GBYS collaborated on several family support events since 2017 that are mentioned in the Goal 6 Program Education and Technical Assistance section. This partnership will continue through 3/31/2024.

The NE-EHDI Program provides support for families with young children identified as DHH through financial and staff support of the Roots and Wings Parent Weekend workshop and/or other Parent Training workshops. A contract with BTNRH is developed annually for the Roots and Wings Parent Weekend. The workshop provides education and networking opportunities for parents with young children who are DHH.

Another resource for family support is through the NE statewide hearing aid loaner bank. The partnership between NE-EHDI and the audiology program at the UNL dates back to 2008. Current details were described in Goal 3.

The Munroe-Meyer Institute (MMI) for Genetics and Rehabilitation in NE is one of 35 Leadership Education in Neurodevelopmental Disabilities (LEND) programs funded by the Maternal and Child Health Bureau for over 25 years to provide comprehensive interdisciplinary leadership training. MMI is also one of 61 University Centers of Excellence in Developmental Disabilities Education, Research and Service. Nebraska's LEND Program serves students completing a graduate or postdoctoral degree from over 13 different disciplines including those most relevant to care coordination planning for children who are DHH, such as Education and Child Development, Audiology, Genetic Counseling, Family Members, and other potentially critical disciplines depending on an individual family's needs. The LEND Director has suggested an idea to develop and enhance leadership experiences through LEND for parents of children who are DHH serving as Guides in the H&V/GBYS as well as other parents interested in expanding leadership skills. PTI-NE provides another opportunity for parents to receive training for leadership, advocacy, and education plans. PTI-NE has extensive experience of training parents in care coordination and supporting models of providing care coordination in primary care practice. The LEND program students can benefit from learning from the parents in PTI-NE and GBYS participating in these trainings, and/or shadowing the guides. Program staff will be able to apply lessons learned from these collaborations in many aspects of program and system administration. NE-EHDI plans to start LEND collaboration efforts early 2020 and will continue to partner with PTI-NE for trainings.

**Goal 6 – Program Monitoring (Reporting, Tracking, and Follow-up):** Program monitoring will occur with the processes already in place with NE-EHDI that were stated in Goals 2 and 3 for H&V/GBYS assisting with follow-up activities. NE-EHDI is also involved with the planning of the family support events with H&V/GBYS. NE-EHDI monitors the data and reporting by the GBYS Coordinator on the follow-up with families and medical professionals on-going in ERS-II. H&V/GBYS reports to NE-EHDI biannually the number of families enrolled with GBYS through EHDI referrals. HearU provides quarterly reports to NE-

EHDI for the number of children served and the number of loaner hearing aids provided to children. BTNRH provides a report to NE-EHDI after the annual Roots and Wings Event of the numbers served and feedback received from families. H&V/GBYS and HearU also report the collaboration work with NE-EHDI biannually to the NE-EHDI Advisory Committee. The collaborations are clearly stated in the separate sub-awards with GBYS and HearU that currently go through 3/31/2020 and renewal sub-awards will be finalized by 4/1/2020.

**Goal 6 – Program Education and Technical Assistance:** There are a variety of family support events that NE-EHDI and H&V/GBYS collaborates on along with other professionals such as RPSDHH, PTI-NE, DHH individuals, and audiologists. A few events to mention include a 6 week workshop about Deaf Culture and ASL presented by a professional Deaf individual; Grandparent and Extended Family workshops statewide; Moms Night Inn Weekend offered twice a year (one in eastern Ne and one in western NE) (topics include – self advocacy, empowerment, literacy, socialization, and communication); ASTra Training (learn about education plans and advocacy); Dads Night Out, Parents Night Out (share experiences raising a DHH child and ask questions); Rising Stars Program to recognize youth who are emerging as DHH leaders; Social Emotional Workshop, and partnering with fire departments and NCDHH for several Fire Safety Events for DHH statewide. NE-EHDI staff provided initial training with protocols for the GBYS Coordinator to conduct EHDI follow-up with families and medical professionals, assisting with care coordination, and referring to EI. On-going technical assistance is provided along with a monthly all EHDI staff meeting.

An annual Roots and Wings parent weekend and/or parent training workshop provides a keynote speaker, plenary and roundtable sessions, and also includes lodging, meals, child care, and social activities for the families. PTI-NE also provides several trainings throughout the year for parents of children with disabilities, which also apply to parents of DHH children. These trainings include assisting families with care coordination, and teaching advocacy and leadership skills for parents to negotiate the educational and health care systems. We will determine the trainings LEND can provide with parents after more planning takes place in 2020.

**Goal 6 – Program Evaluation and Quality Improvement:** This is addressed in A.6. of the Narrative.

**NE-EHDI Goal 7:** Families of young children who are DHH will have access to a DHH Role Model/Mentor.

**Program Objective (as stated by the NOFO) and Outcome Measure for NE-EHDI:**

Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.

**Goal 7 – Program Activities:** NE-EHDI discussed with H&V/GBYS, DHH individuals, deaf educators, and audiologists to see if there is an official DHH Role Model/Mentor Program in NE. It was determined that NE doesn't have an official DHH Role Model/Mentor program per the HRSA NOFO requirements. H&V/GBYS has several individuals listed on their website as DHH Role Models. The information includes a picture, their biography and states if you are interested in being connected with one of the role models to contact H&V/GBYS through the e-mail provided. Even though these are not trained DHH Role Models stated by the HRSA NOFO, H&V/GBYS will report to NE-EHDI the number of individuals during year 1 of the funding period requesting to be connected with one of the role models. H&V/GBYS is also planning during year 1 funding to interview and record the interview with a DHH individual quarterly to be placed on their website

for another opportunity for parents to learn from a DHH individual. Details about program activities for planning and implementing a DHH Role Model/Mentor program are stated in A.6. section of the Narrative.

**Goal 7 – Program Monitoring (Reporting, Tracking, and Follow-up):** Details known at this time are stated in A.6. section of the Narrative.

**Goal 7 – Program Education and Technical Assistance:** Details known at this time are stated in A.6. section of the Narrative.

**Goal 7 – Program Evaluation and Quality Improvement:** Details are stated in A.6. section of the Narrative.

**D. Facilitate improved coordination of care and services for families and DHH children through the development of mechanisms for formal communication, training, referrals and/or data sharing between the NE-EHDI Program and early childhood programs.**

- **By the end of year 1,** recipients will be expected to demonstrate evidence of planning and stakeholder engagement through development of a written plan.
- **By the end of year 3,** recipients should demonstrate evidence of formal communication, training, referrals and/or data sharing.

**D.1** NE-EHDI is already facilitating coordination of care and services for families and DHH children with Individuals with Disabilities Education Act (IDEA) Part C program and N-MIECHV (home visiting) as stated in Goal 3 and discussions have already started with Head Start/Early Head Start for collecting and reporting early childhood screenings, diagnosis, and EI as stated in Goal 4. A written plan with all the details will be in place by the end of year 1. Training, implementation, referrals, and data sharing will be demonstrated by the end of year 3.

**E. Additional work as stated in the NOFO:**

**E.1. Participate in the Annual Early Hearing Detection and Intervention (EHDI) Meeting:**

The NE-EHDI Coordinator, Community Health Educator/Sr. and at least one parent attend the Annual EHDI meeting each year utilizing HRSA EHDI funding and will continue during 2020-2024. The NE-EHDI BAnalyst attends each year utilizing CDC EHDI funding.

**E2.1. Work with the HRSA-20-051 (FL3 Center), HRSA-20-048 (EHDI NTRC), HRSA-16-190 (LEND), and HRSA-18-069 (NRC-PFCMH) recipients to implement the various initiatives that are listed in this NOFO.** This has been discussed in Goals 4, 6 and 7.

**WORK PLAN**

The NE-EHDI Program Work Plan is in Attachment 1 per the NOFO requirements.

**RESOLUTION OF CHALLENGES**

To address the challenge of limited pediatric audiologists in western NE, which was discussed in the Needs Assessment and Goal 1 Program Evaluation and Quality Improvement, tele-audiology was implemented in 2019 through the leadership of NE-EHDI. The goal is to expand in other areas of NE experiencing shortages of pediatric audiologists. This will help improve the percentage of children identified as DHH by 3

months of age and allow more children to be enrolled in EI by six months of age to improve outcomes for children.

NE-EHDI links data with the birth registry in the NE Vital Records program, but does not have the monetary means to link data with other programs such as immunization and blood spot screening. We will continue to explore collaborations to expand the linking of data.

NE-EHDI has collaborated for years with family support organizations and has witnessed through evidence based data and attending family support events how much it benefits families to be connected with family support. With that being said, it is still difficult to distribute 25% of the HRSA EHDI funding to family support organizations and/or organizations providing family support and have enough funding to cover the minimum essential costs of the program even with the CDC EHDI funding. The program had to obtain additional funding through the MCH Title V Block Grant to adjust to the budget changes and requirements of the HRSA EHDI grant and restrictions of how the CDC EHDI funding could be used. NE-EHDI had to reduce staff from two part-time Graduate Audiology students to one and reduce the number of hours in 2017. This position will be paid out of Title V for 2020-2024. We are extremely appreciative of all the funding we receive and that Title V funding is available. At this time NE-EHDI has been informed we will be able to receive Title V funding for the next few years. NE-EHDI will need to request more funding starting 4/1/2020 than what has been requested in the past from Title V. This is so NE-EHDI is able to provide the same amount of financial support to the H&V/GBYS, HearU NE and the BTNRH Roots and Wings family support workshop that families have come to rely on since the total funding amount from HRSA EHDI has been reduced by \$15,000. Also, because the NOFO expectations are to continue providing the same family support as we have from 2017-2020, plus adding support for a DHH/Role Model Mentor Program, and expanding to collect and report data for early childhood hearing screenings to include diagnostic, EI, and family support for children up to age 3. It will be critical to find external partners not only to help decide the format for the DHH Role Model/Mentor Program, but also provide financial support to implement and sustain the program. NE-EHDI has started conversations to partner with Early Head Start to collect and report data for early childhood hearing screenings up to age 3, but that is only a section of that population. It may be difficult to collect and report hearing screens for the entire early childhood population. NE-EHDI plans to discuss with other early childhood programs, and daycares to assess if they provide hearing screens or require the children to have hearing screens. The program will also check if there are pediatric practices providing OAE hearing screens for the early childhood population. The NE-EHDI team is extremely knowledgeable, hardworking, and efficient, regularly utilizing the many resources provided on NCHAM's website, and the information they provide through webinars and trainings. Staff take advantage of conference calls with other EHDI Programs to discuss challenges and successes, as well as attend HRSA and CDC webinars and trainings.

### **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

The evaluation plan during this four year funding cycle will evaluate each step of the logic model for the NE-EHDI Program, which includes the inputs, key processes, outputs, and expected outputs of the funded activities and plans for dissemination. See logic model in Attachment 1. Details of the logic model are explained more through the goals and their stated program activities; program monitoring; education and technical assistance; and evaluation and quality improvement in the Methodology section. These also describe how the program will measure the extent to which the NE-EHDI program meets the program-specific goals, objectives, and requirements in the purpose section of the NOFO. The vast amount of data

that is collected through ERS-II and the various reports developed and utilized permit the NE-EHDI Program to continuously monitor each level of the EHDI system and initiate change when necessary. A.6. in the Narrative describes how NE-EHDI has selected expansion of screening up to age 3; and family engagement and family support to include implementing the DHH Role Model/Mentor Program for the two QI projects to be reported annually during the four year project period.

### **ORGANIZATIONAL INFORMATION**

NE-EDHI is located within the Newborn Screening and Genetics Program, Lifespan Health Services Unit, Community and Environmental Health Section, Division of Public Health, Nebraska Department of Health and Human Services (NE DHHS).

The structure of the NE DHHS includes the Chief Executive Officer (CEO), who is appointed by the Governor and confirmed by the Legislature, and who directs the responsibilities and work of the Department with direct oversight of six divisions and eight operational areas. The six Division Directors, who are appointed by the Governor and confirmed by the Legislature, report to the CEO. The divisions are Behavioral Health, Children and Family Services, Developmental Disabilities, Medicaid and Long-Term Care, Public Health, and Veterans' Homes. Operational areas include Communications and Legislative Services, Information Systems and Technology, Legal Services, Human Resources and Development, Support Services, Internal Audit, and Operations Consulting. In addition, a Chief Financial Officer reports to the CEO and oversees Financial Services.

DHHS provides important and oftentimes life-sustaining services to Nebraskans. Our mission, "Helping People Live Better Lives," provides the motivation to effectively provide these services and make a difference in the lives of hundreds of thousands of people. DHHS is Nebraska's largest state agency, responsible for nearly one-third of state government in terms of employees and budget. Agency-wide values guide employees in achieving this mission and effectively implementing the state and federally-mandated programs and services that assist Nebraskans. These values include: constant commitment to excellence, high personal standard of integrity, positive and constructive attitude and actions, openness to new learning, and dedication to the success of others.

The Division of Public Health's core functions and essential services, include assessment, policy development, and assurance, along with the five priorities: becoming a trusted source for health data, addressing health disparities, devising a media and education plan, creating a culture wellness, and providing budget transparency are in alignment with the HRSA EHDI funding requirements and expectations, which will assist the program in meeting the requirements. It is explained throughout the Narrative the numerous collaborations NE-EHDI has with other programs within NE DHHS and with other state agencies which lay the foundation for a successful EHDI system, and many discussions have begun for new collaborations in the future.

NE-EHDI Program has an advisory committee that meets biannually and includes representation from multidisciplinary programs. The advisory committee provides direction and guidance to the NE-EHDI Program. See the Methodology section for more details.

The NE-EHDI Program receives funding from the HRSA EHDI, the HRSA Title V Block Grant, and the CDC. The HRSA EHDI grant funds the basic operations of the program. The CDC cooperative agreement

primarily funds the development, implementation, maintenance, and expansion of the integrated electronic data reporting and tracking system (ERS-II). The HRSA Title V Block Grant helps fund basic operations of the EHDl program when there isn't enough funding from the other sources and/or isn't allowed in the other funding sources.

The percentages listed below for each position show the amount of time personnel give to the NE-EHDl Program and does not indicate the percentage of cost paid by the HRSA EHDl funding. **For more details, see the Budget Narrative and Attachment 3: Biographical Sketches of Key Personnel and Attachment 5: Project Organizational Chart.**

- Program Manager (1.0 FTE) Brenda Coufal, BS:
- Community Health Educator/Senior (1.0 FTE) MeLissa Butler, BS
- Business Analyst (Contract .85 FTE) Jim Beavers
- Community Health Educator (Temporary .30 FTE) Jennifer Lee, BS
- Community Outreach Coordinator (Contract/sub-award .40 FTE) Shelli Janning, MSHS

NE-EHDl is fortunate to have a fully functional program with skilled staff that share the program's vision and values, who perform their duties competently, and work well together contributing to a positive team atmosphere. Another strength for the program is that the full-time Community Health Educator/Sr. and Business Analyst have worked together for several years, and the Newborn Screening and Genetics Program Manager of over 20 years provides guidance and strong support. The NE-EHDl Program is nationally recognized as a high quality and effective program.

NE-EHDl receives in-kind support at the community, state, regional, and national levels through collaborations with birthing hospitals; audiologists; advisory committee members; EDN, the Part C Early Intervention Program; MHCP that is part of the CYSHCN; RPSDHH; PTI-NE; H&V/GBYS; DHH community; N-MIECHV; and WIC. Each of these provide at minimum one of the following services: reporting and tracking data; providing education about the EHDl system; engaging families in the EHDl system; and providing family support; referring and/or enrolling in EI services and family support programs. See Methodology Goal 3 for more details.

### **RESOURCES/CAPABILITIES**

The NE DHHS's ability to conduct the program requirements and meet the program expectations through the NE-EHDl Program are explained in the organizational information in the previous section of this narrative. The capacity of NE DHHS and NE-EHDl to engage families, health professionals, and service providers are stated throughout the goals in the Methodology section of this Narrative. How NE DHHS and NE-EHDl will follow the methodology and plan, routinely assess and improve the services for the unique needs of the target populations and the communities served, and NE DHHS's experience working with the EHDl system are stated in the Methodology and Organizational Information sections of this Narrative. The details about the NE-EHDl electronic data system for capturing data for hearing screening, refers and follow-up, diagnosis, EI, family support; reports for internal program improvement; NE Legislature; federal funders; and the names of all of our collaborative partners to provide a high quality EHDl system for families and children in NE are included in the Methodology section of the Narrative.