INTRODUCTION

Diagnosed at birth with multiple conditions and battling infections resulting in several hospitalizations, the fact that this child could not hear was overlooked. This is the true story from one North Dakota family: *"When my daughter was born, newborn hearing screening was not part of the testing which was completed in the hospital after birth. After reoccurring ear infections and extremely delayed speech, as a parent, I started to push the issue of further testing. After several tests and a lot of inconclusive results, she was finally diagnosed with a hearing loss. After 5 years of not being able to hear and the frustration of no one understanding her communication, she was fitted with a hearing aid. Her life was changed forever. She went from the shy little girl who hid behind my leg, to a girl who stood center stage singing a solo at the Christmas concert. She also has stood in front of crowds of hundreds of people to dance. Although my daughter was able to excel in later life, I can't imagine the difference early intervention would have made in her life. She went through 5 years of being unable to communicate her needs, wants and desires to the people who loved her." D. Anderson-ND Parent.* This story exemplifies the importance of having a Early Hearing Detection & Intervention (EHDI) system of care.

North Dakota's EHDI (ND EHDI) program began in 2000. At present, North Dakota (ND) has two projects supporting EHDI efforts. The ND EHDI program initially received funding from the Health Resources and Services Administration (HRSA) in 2000 to implement universal newborn hearing screening and the ND EHDI Information's Systems (ND EHDI-IS) project began with funding from the Centers for Disease Control and Prevention (CDC) in 2005. ND does not have legislation mandating hearing screening or the reporting of results.

North Dakota is a remarkably rural state with a population of 760,900 (census estimate 2019). Only Alaska, District of Columbia, Wyoming and Vermont have fewer residents; however, North Dakota's current population growth rate is the second in the nation at an astounding 1.99% (North Dakota Population. (2019-06-05), http://worldpopulationreview.com/states/north-dakota/). The population growth has been the result of in-migration which has also increased diversity in racial and ethnic background. While American Indians have remained the largest minority group, they no longer represent the majority of the minority (34% in 2016) (Commerce.nd.gov, Aug 2017.pdf). The state's average population density is only 9.7 people per square mile with 46% of the total population residing in 5 cities. ND covers 70,698 square miles and the nation's 19th largest state (www.mapsofworld.com). The ruralness and geography necessitates the need to expand and support a comprehensive coordinated EHDI system of care so families with newborns, infants and young children up to age 3 who are deaf or hard-of-hearing (DHH) receive appropriate and timely hearing care services including hearing screening, diagnosis, early intervention (EI) and family support.

While ND EHDI has seen positive impacts, definite barriers and challenges remain. The latest ND 2017 CDC Hearing Screening and Follow-up Survey (HSFS) indicates 97.8% of infants completed the screening process at no later than 1 month of age. While this meets HRSA's objective of screening at least 95% of infants and exceeds the national average of 94.8% (CDC HSFS, 2016), the ND 2017 HSFS also indicates that of the total not passing the hearing screen only 14.2% have a documented diagnosis before 3 months of age with 62.5% of those diagnosed

with permanent hearing loss becoming enrolled in EI services no later than 6 months of age. To address these deficits, ND EHDI will work with ND's health professionals and service providers such as EI programs and family support organizations (FSOs) to enhance and strengthen ND's capacity to improve these rates as well as outcomes and coordination of care for families and their children through family-based supports such as family-to-family and adult consumer-to-family DHH programs.

North Dakota has engaged in a wide range of activities to improve hearing screening, diagnosis and subsequent referral to EI and family support services. While ND's occurrent birth rate continued to increase from 2014-2016, the total number of infants not passing the final screen continually reflected a notable decrease. Documented number of diagnoses (DHH and normal hearing) has varied between years as has enrollment in EI; however, proposed strategies to improve timely, complete audiological reporting will improve diagnosis rates and timely EI services. It is important to note that while the loss to follow-up/loss to documentation (LTF/LTD) *percentage* has shown a slow improvement, the *actual number* of infants LTF/LTD greatly decreased. (Figure 1)

Year	Total Births	Total Not Pass Screening	DHH Diagnosis	Normal Hearing Diagnosis	EI Enrollment < 6 months of age	LTF/LTD
2013	11,978	404	18	75	10 (80%)	246 (60.9%)
2014	12,840	362	24	78	14 (64.3%)	191 (52.8%)
2015	12,829	310	14	69	9 (44.4%)	139 (45.1%)
2016	12,954	314	13	62	10 (50%)	149 (47.5%)
2017	12,388	282	23	60	16 (62.5%)	136 (48.2%)

Figure 1

Over the past nineteen years, ND EHDI has continued to successfully implement and build upon the EHDI system of care in ND. Some accomplishments are:

- Supported the Joint Committee on Infant Hearing (JCIH) protocol of *newborn hearing screening practices* within the birthing facilities.
- Initiated and conducted *collaborative efforts* within communities and a *referral process* to EI and FSOs for infants diagnosed DHH.
- Supported and managed a *statewide hearing health information system* for *coordination of care efforts* and the *engagement of family* leaders *within the ND EHDI system.*
- Provided *continued education and technical assistance* to hearing health professionals and service providers.

Throughout the next grant cycle, ND EHDI will focus on three categorical areas: 1) Stakeholder and Professional Engagement, 2) Family Engagement and Early Childhood Coordination and 3) Collaboration. To accomplish this, the ND EHDI program has proposed five goals which incorporate the HRSA EHDI Notice of Funding Opportunity (NOFO) directed objectives.

Purpose of Proposed Project: The ND EHDI program requests funding to continue, as stated and in alignment with the HRSA Program Purpose (HRSA-20-047), *"to support a comprehensive and coordinated state EHDI system of care so families with newborns, infants and young children up to 3 years of age who are deaf or hard-of-hearing (DHH) receive*

appropriate and timely services that include hearing screening, diagnosis and Early Intervention (EI).”

In response to the NOFO, the ND EHDI Program proposes goals, objectives and activities to support the continued work t*o attain the HRSA Program Goal (HRSA-20-047) “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 EI to optimize language, literacy, cognitive, social and emotional development.”*

Methods: The **methods proposed** within the stated goals and objectives will include an extensive array of activities including education, training, technical assistance, coordination of community EHDI stakeholders, meetings, information dissemination, development of written plans to meet objectives and goals (Attachment 1: Work Plan and Logic Model).

Projected Outcomes: The primary expected outcome will result in health professionals, service providers and families who are knowledgeable of a comprehensive EHDI system of care is and can incorporate EHDI directed methods into their practices and lives to ensure newborns, infants and young children up to 3 years of age who are DHH receive appropriate and timely services including hearing screening, diagnosis and EI. To support the primary outcome, the following supporting **outcomes** are **projected**:

- Developmental outcomes of children who are DHH are improved.
- Increase by 1 percent from baseline per year or achieve at least a 95 percent screening rate 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.
- Reduced loss to follow-up/loss to documentation (LTF/LTD) rates.
- State capacity to support hearing screening in children up to 3 years of age is increased.
- Families with children who are DHH and adults who are DHH engaged throughout the EHDI system.
- Increased self-advocacy.
- 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.
- Family support capacity is strengthened.
- Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.
- Health professionals and service providers are engaged and educated on the EHDI system, 1-3-6 recommendations, the need for hearing screening up to age 3, the benefits of a family-centered medical home, and the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to families.
- Improved coordination of care and services for children who are DHH and their families.

The collaboration of current and new state EHDI partners will ensure progress in meeting the proposed goals and objectives. ND EHDI staff will provide education, training, technical assistance and guide community coordination to support EHDI stakeholder engagement. The long history of the ND EHDI program speaks to the continued commitment to maintain, expand and improve a comprehensive EHDI system of care in ND.

NEEDS ASSESSMENT

ND EHDI System: Historically, the ND EHDI approach to assuring timely and complete infant hearing care has been based on efforts to increase timeliness at each stage of hearing health care, decrease LTF/LTD, increase efforts ensuring coordination of care and education for providers and families. At the time of a hearing loss diagnosis, ND EHDI staff assure appropriate referrals are made to EI programs to facilitate the support and education of families and involve them with FSOs. ND EHDI staff also provide information and opportunities for families to connect with additional resource programs such as those offered through the North Dakota Department of Health (NDDoH).

While great improvements have been made, the ***need*** *still exists to* ***enhance provider and family awareness*** *through* ***engagement*** *and* ***education*** *in the EHDI process.* The 1-3-6 JCIH recommendations, which are to screen by 1 month of age, diagnose by 3 months of age and enroll in EI by 6 months of age, are the foundation on which the EHDI system of care establishes timelines and measures progress in providing the continuation of care to promote optimal outcomes.

This application will ensure families of newborns, infants and young children up to age 3 who are DHH receive appropriate and timely services throughout the screening, diagnosis, EI and family support processes. North Dakota EHDI will increase education, engagement and coordination of stakeholders. North Dakota EHDI will also increase family education and engagement opportunities to empower families and improve early childhood care coordination assuring all resources are being utilized to support families. Some of the strategies incorporated will continue proven methods from previous grant work while others expand upon existing strategies. *Additionally, there is a* ***need for expansion*** *and* ***diversification*** *of partners/programs to include the NDDoH, Family Voices of North Dakota (FVND) and Early Head Start programs to promote and assure a coordinated EHDI infrastructure is developed.*

Stakeholders: Throughout ND EHDI's longevity, the program has been able to establish and maintain an incredible network of completely voluntary based and/or memorandum of understanding (MOU) driven partnerships with ND's hearing health care providers and vested hearing support programs. Partners have included but are not limited to all birthing hospitals, the North Dakota American Academy of Audiologists (NDAAA), American Academy of Pediatrics (AAP), North Dakota School for the Deaf (NDSD), Parent Infant Program (PIP), the state's EI programs (Right Track and Part C Infant Development), Tribal Tracking, local public health units, North Dakota Center for Persons with Disabilities (NDCPD) a University Center of Excellence on Developmental Disabilities, Education, Research and Services (UCEDD), North Dakota Health Information Network (NDHIN) and FSOs including ND Hands & Voices (ND H&V) and Family Voices of North Dakota (FVND). Collaborative efforts also include multiple

divisions under the North Dakota Department of Human Services (NDDHS) and NDDoH including Vital Records, Maternal Child Health (MCH) Title V Children and Youth with Special Health Care Needs (CYSHCN) program/Special Health Services (SHS), the Newborn Screening Program (NBS), North Dakota Developmental Disabilities Division and the Minnesota EHDI (MN EHDI) program. *ND EHDI has a great **need** to **expand statewide partnerships** to enhance and support hearing screening of children up the age of 3, including data collection and reporting as well as sharing educational materials to promote JCIH recommendations.*

If awarded, there will be an ongoing need for ND EHDI to reassess partnerships throughout the grant period. To facilitate a statewide coordinated EHDI expanded infrastructure and accomplish program improvements, ND EHDI will reassess and revise partnerships identified by gaps within each area of hearing health care.

Performance of 1-3-6 Recommendations (*Decreasing LTF/LTD):* *There is an imperative need for ND EHDI to receive complete documentation of hearing care results throughout the screening and diagnostic process to decrease LTF/LTD.* This allows for the true identification of infants that are LTF and decreases time spent tracking outcomes thought to be incomplete but found to be LTD.

Over the past years, several factors have attributed to LTF/LTD. While screening rates have consistently remained above 97%, the birth screen refer rate has been elevated leading to a greater number of infants requiring follow-up. Loss to follow-up between screening and diagnostics remains a concern as there has been a noted decline in audiologists self-reporting outpatient rescreen and diagnostic outcomes. In 2017, ND had an acceptable screening rate (97.8%); however, the statewide average birth screen refer rate was 10% with 5 of 12 birthing facilities reporting detrimentally elevated rates at 15% or higher. (ND's target birth screen refer rate is 4% to 6%.) The overall LTF/LTD rate of infants not passing the screening was reported to be 48.2%. *ND EHDI staff have a tremendous **need** to **provide training** and **refresher trainings** to providers at all levels in the hearing care process and identify additional strategies to overcome these issues.*

While many providers (hospitals, audiologists, EI providers, DoH SHS and FSOs) have direct access to ND EHDI's online secure data system called OZ eSP from OZ Systems, Inc., *there is a great need to assure all providers are knowledgeable of and utilize reporting methods to report timely, complete outcomes to ND EHDI.* The ND EHDI program utilizes three "methods of documentation". For birthing hospitals, *there is a need to promote an OZ eSP functionality called Telepathy at hospitals currently manually entering birth hearing screening results.* Of ND's 12 birthing facilities, 4 larger facilities accounting for 52% of ND's births have not implemented or fully implemented Telepathy. Telepathy eliminates the need for hospital staff to manually enter results, eliminates data entry error and ensures screening results are easily imported. Secondly, *there is a **need** to **promote direct access to OZ eSP** for providers without access and provide training.* Furthermore, *there is a **need** to assure all screening, diagnostic, EI **providers and partners are knowledgeable** of the ND EHDI secure online submission form and faxback form **for reporting of results**.*

*There is a **need** to identify and facilitate partnered program **referrals** in OZ eSP **to decrease LTF/LTD**.* North Dakota's partnered programs play an important role in assuring families are educated on the importance of complete hearing care which promotes follow-up and a decreases LTF. Once a partnered referral is entered into OZ eSP, the added entity will receive a secure email notification within 24 hours containing a confidential identification number giving the added provider access to the child's record to facilitate timely outreach and support to the family. Referrals to partners increase statewide program supports/education for families allowing them to make informed decisions and promotes complete, timely follow-up and decreases LTF/LTD.

ND EHDI has made remarkable progress in reducing LTF/LTD. North Dakota's first year of complete CDC survey reporting was in 2006. In 2006, ND EHDI identified 8,219 births with a 93.6% LTF/LTD (2006 CDC HSFS); the 2017 CDC HSFS indicates 12,388 identified births with a 48.2% LTF/LTD representing a reduction in the LTF population from 400 to less than 150 infants. Yet, even with the noted LTF/LTD rate improvement, ND EHDI has and will encounter challenges decreasing this rate. *There is a great **need** to **collaborate** with partners to **overcome needs** and **barriers** including ND's statewide ruralness (distance parents must travel); 20,789 children living in poverty,13,590 uninsured children (KIDS COUNT, 2017) and lack of local diagnostic services for families which contributes to the LTF rates in ND* (Attachment 8: ND Audiology Provider Map).

1-3-6 **Screening Process:** North Dakota does not have a mandate for infant hearing screening or reporting; however, ND EHDI and families are fortunate all birthing hospitals in our state voluntarily promote infant hearing screening as a standard of care and willingly report outcomes to ND EHDI. *There is a tremendous **need** to **continue partnerships** and support birthing facilities to facilitate prompt identification of births and timely reporting of birth hearing screen outcomes to ND EHDI.*

North Dakota is a two-stage hearing screening state. Despite the lack of legislation, ND EHDI has achieved a 97.8% screening rate (2017 HSFS). Birth hearing screens are primarily conducted by birth hospitals. Outpatient screens are completed by some pre-Part C programs, hospital nurseries or at an audiology hearing center. Utilizing the OZ eSP data system, ND EHDI staff monitor/track screening and diagnostic outcomes on a weekly basis. Analysis of these outcomes allows for identification of issues and trends, e.g., increased refer rates, decreased timely documentation, lack of documentation and LTF. The ND EHDI staff has greatly enhanced complete, timely screening and documentation by birth and outpatient screen providers through identifying issues, timely technical assistance (TA) and training. Complete, timely screening information is imperative as it is often the crucial foundation for the identification of many cases of hearing loss and the assurance of EI and additional supports being offered to families. The TA sessions also provide education to nursery and outpatient providers increasing provider proficiency in use of the data system to identify specific populations requiring attention such as LTF/LTD rates and assures well-informed providers are capable to educate families on the importance of complete hearing care related to 1-3-6 recommendations. Furthermore, the TA provided by ND EHDI staff promotes providers engagement, self-reliance and the ability to establish methods within their practices to promote follow-up attendance/completion. Due to staff turnover and process changes, *there is a significant **need** for **continued data monitoring** and provision of **technical assistance**, **training** and **education** for **hospital** and **outpatient***

providers *to achieve and improve the screening and diagnostic rates, decrease the LTF/LTD, enhance provider knowledge assuring families are well informed of 1-3-6 guidelines and promote infrastructure.*

1-**3**-6 **Diagnostic Process:** About 2-3 out of every 1,000 children in the United States are born with a detectable level of hearing loss in one or both ears (National Institute on Deafness and Other Communication Disorders, 2016). North Dakota's 2017 HSFS indicates a total of 12,388 births with 23 infants being diagnosed with a permanent hearing loss (1.9 per 1000 prevalence rate); however, the survey also indicates of the total not passing the hearing screening only 14.2% have a documented diagnosis before 3 months of age. While ND is close to the statistical benchmark for identified number of infants with a diagnosed hearing loss, factors remain which inhibit completion of recommended diagnostic care and complete data collection of diagnosed hearing loss outcomes.

In North Dakota, the pediatric audiologists completing diagnostics are only located in the four largest cities in central and eastern ND (Attachment 8: ND Audiology Provider Map). Infants referred on an outpatient screen generally must travel to one of these locations to have diagnostics completed. The rural topography of ND contributes to the willingness and/or ability to return for audiological follow-up with additional factors including lack of concern or budgetary constraints. Service providers often contact ND EHDI staff indicating a hearing loss has been reported by a family, however, ND EHDI does not have documentation of the hearing loss outcome in OZ eSP. While most audiologists in ND have been trained on data entry into OZ eSP, the overall lack of reported diagnostic outcomes has limited the number of cases of normal hearing or permanent hearing loss identified and timely assurances of complete referrals/supports for families and their children. *There is a tremendous* ***need*** *for continued data monitoring and the provision of* ***technical assistance****, OZ eSP* ***training*** *and* ***education*** *for* ***ND's audiologists*** *to improve timely diagnostic reporting, decrease LTF/LTD and enhance provider knowledge assuring families are well informed of 1-3-6 guidelines and EI supports as afore mentioned in "Screening Process".*

Of the 23 cases of permanent hearing loss documented on the 2017 HSFS, ND EHDI, through follow-up efforts, identified and documented 19 of the cases. The 2017 HSFS also indicates of the infants diagnosed, only 48.3% were identified with normal hearing at less than 3 months of age and 47.8% were identified with a permanent hearing loss at less than 3 months of age. *There is a* ***need*** *for ND EHDI to seek assistance from vested statewide partners to help* ***identify/explore*** *additional* ***strategies*** *to* ***improve diagnostic rates of completion*** *and the reporting of diagnostic outcomes.*

1-3-**6-Early Intervention:** At present, ND EHDI utilizes OZ eSP to assure appropriate referrals are made to EI providers and support programs who promote follow-up, assure complete hearing care and support/education is being offered to families. These programs include pre-Part C Right Track, Part C Infant Development, the NDSD PIP and Tribal Tracking. North Dakota EHDI's EI referral process is different than many states who initially refer to EI at the time of a hearing loss diagnosis. In ND, a referral is placed with the pre-Part C program, Right Track, after a second stage (outpatient) hearing screening refer outcome. Right Track is a 0-3 year of age program providing families with support to assure a hearing diagnosis is obtained when a higher risk for

hearing loss has been identified. At the time of a permanent hearing loss diagnosis, most families transition from Right Track services to Part C Infant Development and NDSD PIP services. Due to changes in the referral process, lack of EI provider OZ eSP proficiency and EI staff turnover, *there is a great **need** for ND EHDI to **monitor** EI data and **provide TA and training** to **EI providers**.*

The 2017 HSFS indicates that of the 23 infants diagnosed with a hearing loss, 3 were non-residents considered ineligible for ND EI services (and were referred to their home state EHDI program for follow-up). Of the 20 ND residents diagnosed with hearing loss, all were referred for EI services and 4 families declined. Of the remaining 16 families, 10 received Part C or Non-part C services prior to 6 months of age (62.5%). *There is a **need** for ND EHDI to **identify** and **implement strategies** to improve timely documentation of the hearing diagnoses allowing for **earlier EI referral/support**. There is also a **need** for ND EHDI to educate ND's EI providers about family support to ensure **family support** is **offered**, expanding services for families **through** a **coordinated infrastructure**.*

The communication and collaboration between ND EHDI and EI partners are an important means to increasing the number of infants identified to be DHH that are enrolled in EI services before 6 months of age. While ND EHDI and Part C have had a strong relationship for many years, the lack of a data sharing agreement has been a barrier in assuring EI information can be seamlessly shared between partners. *There is an imperative **need** for ND EHDI to continue **collaborating** with the **ND Part C** to complete a **data sharing agreement**.*

Family needs: Families have verbalized the importance of connecting with other parents. It is imperative for parents to hear a voice of personal experience that is not the clinical advice often coming from hearing professionals. Families of infants who are DHH need to have positive parent-to-parent support in their new role. An FSO can help families through the lens of lived experience to discover and understand their role as the parent of a child with special needs. The FSOs work closely with families and EI to help parents learn to find resources, advocate for their child, prepare for important life transitions and gain confidence in navigating systems as their child grows. One ND parent of a DHH child expressed what they would like to see achieved through the ND EHDI system, *"My hope as a mother of a child with hearing loss is that everyone working in the area of childhood hearing loss will continue to strengthen our systems of resources and support; and that all the families will feel empowered to join in the local activities available for them." J. Harkins, Parent and ND H&V Board Member. (ND EHDI Newsletter, Winter 2018)*

A national needs assessment conducted in 2018 by the Family Leadership in Language and Learning (FL3) stated *"that of families surveyed with children who are DHH under the age of 6, only 28 percent of these families were offered formal parent-to-parent support program services and only 27 percent of these families were offered access to an adult who is DHH as a mentor, role model, or guide."* This statement aligns with ND EHDI findings. As ND EHDI continues to collaborate with FSOs/family leaders *there is a significant need to expand family support services for families.* During the current grant cycle, ND H&V were the recipients of the 25% funding for family engagement and family support activities. Although the foundation of the ND H&V organization was strengthened through the implementation of the Guide By Your Side

(GBYS) program, more resources in the form of services are needed for families of children who are DHH. *There is a **need** in ND for **dual collaboration** by the FSOs (ND H&V and NDFV) to **improve capacity** and **expand infrastructure** to **strengthen coordination of care**, **provide** family support **partnerships**, **leadership** opportunities and **engagement** for families with children who are DHH and adults who are DHH throughout the EHDI system.*

Community visits: ND EHDI has conducted various presentations and educational materials to stakeholders and health care providers; however, a successful method or means to increase knowledge and engagement of vested partners and families within the EHDI system has not been fully implemented. This has left gaps in assuring professionals have the awareness and/or complete knowledge of ND's EHDI system of care and JCIH protocols. Taking this into consideration along with the lack of a fully established comprehensive and coordinated system of care which also encompasses the need for screening up to age 3 and indicates the benefits of family centered medical home, *there is an essential **need** for **community visits** to be reinstated and expanded.* The re-initiation of Community visits will fulfill these needs and address additional requirements within this application.

Outreach/Education: *There is a **need** for ND EHDI to include **partners** in **expanding** statewide **outreach/educational** efforts.* During past funding cycles, ND EHDI staff have been the primary source for providing state-level outreach and increasing EHDI stakeholder knowledge/education regarding EHDI services and protocols of best practice. While this initiative has been successful to a point, ND EHDI is mindful of additional methods which can be employed to expand and sustain a comprehensive statewide system of care. *ND EHDI has a need to implement quality improvement activities to monitor and assess program performance in the areas of **provider outreach and education** and **family engagement and family support** and disseminate findings in an annual report.*

Additionally, *there is a **need** for ND EHDI to **conduct outreach** and **education** to health professionals and service providers via community visits to address 1-3-6 recommendations, screening up to age 3, family-centered medical home and the importance of relaying current and accurate unbiased information to families.*

To support a comprehensive and coordinated system of care for families, *ND EHDI has the **need** to utilize TA and collaborate with federal and state partners to **promote evidence-based educational opportunities and materials**.*

*There is a **need** to conduct **outreach** and **education** via various methods **to engages families** throughout all aspects of the ND EHDI program.* Over the past grant period, ND EHDI identified the importance of parent-driven advocacy to enhance the EHDI system of care enabling children who are DHH to reach their highest potential. *There is a **need** to **strengthen** the **capacity** to engage and educate **families with children** who are DHH as well **adults** who are **DHH** throughout all aspects of the ND EHDI program.*

Target populations: North Dakota is in the northern Great Plains and is an extremely rural state. Over the past decade, ND has become more diverse with regards to race, ethnicity, gender identity, sexual orientation, geography, socio-economic status, disability status, primary

language and health literacy. The **geography** of ND indicates 36 of 53 counties are designated as Frontier with less than 6 persons per square mile (UND Center for Rural Health, 2016 https://ruralhealth.und.edu/maps). The rural/frontier designations are important as they significantly impact service access and delivery. *This necessitates ND's **need** to **expand** and support **coordinated care efforts** due to ruralness and harsh winters of ND.*

According to the 2019 ND Kids Count data (www.ndkidscount.org), **race and ethnicity** have important implications for culture, identity and overall well-being. While racial and ethnic minority children continue to represent a relatively small percentage of ND's youth, the state is continuing to become more diverse. The number of black, Asian and American Indian children combined grew four times faster than white children from 2010 to 2017. The number of Hispanic youths grew nine times faster than the number of non-Hispanic children. North Dakota's **primary language** is English. According to The Patient Protection and Affordable Care Act of 2010, Title V, Health literacy is defined as "the degree to which an individual has the capacity to obtain, communicate, process and understand basic health information and services to make appropriate health decisions." To date, no supporting evidence to measure the "**health literacy**" of ND residents as it pertains to the EHDI system of care has been found. In 2017, North Dakota ranked 3rd in the nation for lowest percentage of individuals with a **disability**, and the **population gender** breakdown in ND was 389,350 males and 370,727 females (www.ndcompass.org/demographics). According to the Movement Advancement Project (MAP, http://www.lgbtmap.org/equality_maps/profile_state/ND), the total lesbian, gay, bisexual and transgender (**LGBTQ+)** population in ND is 15,697 representing 2.7% of the state adult population. (https://www.ndcompass.org/demographics/index.php). *With an increased diversity in ND, there is a **need** to **increase cultural and linguistic competencies** by empowering stakeholder to engage and promote inclusion of all race/ethnicity, language, health literacy, disability, sexual orientation, gender and other status. Additionally, there is a **need** to assure **families receive accurate, comprehensive, up-to-date and evidence-based communication**, in a timely and culturally sensitive format at all stages of the EHDI system.*

In ND, t**he socio-economic status** of the median household income for families with children grew to $79,077 in 2017, up 10 percent from 2010. The child poverty rate was 12 percent. A significant disparity exists in ND with respect to age, race and ethnicity and family structure. Families in ND continue to struggle to cover basic expenses for housing, food, transportation, health care and childcare. Over 13,590 ND children lack some form of health insurance coverage; however, government programs such as Medicaid, WIC, Waivers, NDDoH Diagnostic and Treatment programs and Healthy Steps supplemental forms of coverage have been provided for these children. Children living on reservations tend to have the highest child poverty rates in ND (https://www.ndkidscount.org). *There is a **need** to assure **families** are **made aware of all programs** providing financial supports to promote timely complete hearing health services.*

It is important the ND EHDI team be aware of ways in which cultural patterns of families can affect the development of collaborative partnerships. While it is critical to remember to respect the diversity that occurs within cultural groups, it is also important to be aware of various culturally influenced factors. *There is a **need** to explore methods/plans and collaborate with state partners/ stakeholders to address **diversity and inclusion** in the EHDI system within first-year funding. There is also a need to maintain, improve and promote an accessible and culturally*

appropriate website and social media platforms that encompass accurate, comprehensive and evidence-based information.

Advisory Committee (AC): *There is a need to maintain the Advisory Committee (AC) to promote optimal developmental outcomes of newborns, infants and young children.* The AC is currently comprised of a diverse inclusive group of health care professionals and parents/family member that provide knowledge, expertise and experience obtained from within their career and/or life experiences. *There is a **need** for ND EHDI staff to maintain, expand and recruit a **diversified and inclusive AC** comprised of a **minimum of 25% parents of children** who are DHH and **adults** who are **DHH**.*

Sustainability: *There is an immense **need** to discuss key aspects and explore the **development** of a **written sustainability plan** in collaboration with the AC, state stakeholders and FSOs.* North Dakota does not have legislation that mandates hearing screening and/or reporting. The state does not provide any fiscal support to ND EHDI for program efforts. Without current funding sources, there would be no EHDI network or standards to promote hearing health care in ND. The ND EHDI program will address sustainability through system changes and embedded process implementation to maintain a website, services and interventions.

Evaluation: The evaluation of ND EHDI program effectiveness has most consistently been completed through the reporting of data collection efforts. To understand how the ND EHDI program functions, the ***need** to develop a **comprehensive evaluation plan** is necessary*. Implementing the plan within the regular function of the ND EHDI program will enable ND EHDI and various EHDI stakeholders to view program effectiveness and identify gaps and barriers in the system (see Evaluation and Technical Support Capacity).

Annual EHDI Conference: *There is a **need** to provide **professional development** through education and networking opportunities to **support leadership activities** within EHDI systems.* Attending the national conference allows participants the opportunity to develop networks and program improvement ideas. These opportunities for families, family leaders, and EHDI professionals is, in part, what strengthens EHDI programs. As required by the NOFO, ND EHDI will support the attendance of one or two ND EHDI staff and one family leader to the annual EHDI meeting.

METHODOLOGY

STAKEHOLDER AND PROFESSIONAL ENGAGMENT

Goal 1: By March 31, 2024, ND EHDI will lead efforts to engage and coordinate all state stakeholders to improve the ND EHDI system of care promoting optimal developmental outcomes for newborns, infants and young children who are DHH.

Objective 1.1: By March 2024, ND EHDI will reduce loss to follow-up/loss to documentation (LTF/LTD) and support a coordinated infrastructure to 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.

Activity 1.1.1: *ND EHDI will continue to monitor screening outcomes statewide and provide technical assistance to birth screen and outpatient providers.* ND EHDI staff will continue to support the partnerships with birthing hospitals and promote complete, timely screening and documentation via weekly monitoring of screening outcomes reported in the OZ eSP system. ND EHDI's weekly analysis of the screening data facilitates timely one-on-one TA/training/education to the individual facility or provider at the time of identified issue(s) whether it be increases in refer rates, missing outcomes, lack of timely follow-up, etc. This directive will be continued as it has proven to effectively increase provider knowledge leading to the development/implementation of protocols/strategies by providers strengthening their internal infrastructure based on their individual issues.

Activity 1.1.2: *Promote the installation of Telepathy functionality, data system accessibility and alternate reporting options.* To decrease LTF/LTD and address the need assuring providers have access to reporting hearing results, ND EHDI will assure 3 methods of data reporting are implemented and/or made available to all providers. 1) OZ eSP Telepathy functionality (import of screening results): At present, 3 birthing facilities are incapable of implementing the OZ eSP Telepathy functionality due to lack of current instrumentation capabilities. ND EHDI in collaboration with OZ Systems, Inc. will work with the 3 hospitals to assure future purchased instrumentation is Telepathy compatible. Additionally, ND EHDI will continue to support four birthing facilities who have instruments capable of Telepathy but have not implemented or fully implemented the functionality, 2) Direct OZ eSP Access: ND EHDI will promote and provide training for additional hospital and outpatient providers to have direct OZ eSP access for result entry, 3) Online/Fax-Back Reporting: ND EHDI will assure all providers are knowledgeable of the availability to report hearing care outcomes via a secure online submission form or a fax-back form available on the ND EHDI website.

Activity 1.1.3: *ND EHDI will conduct community visits.* Prior to the last round of funding, ND EHDI conducted yearly "community visits" at each birth facility. The visits are missed by community EHDI stakeholders and were an impactful means of bringing together each community's hearing health care partners in one place, at one time, for a face-to-face meeting identifying their system of care toward assuring complete timely hearing health care for ND's infants. Community visit participants included but were not limited to hospital nursery supervisors (well-baby and NICU), hospital screeners, nursery clerical staff, outpatient screen providers, audiologists, ENTs, pediatricians, neonatologists, primary care physicians, hospital CEOs, regional EI providers including Right Track (pre-Part C), Infant Development (Part C), the Parent Infant Program from the NDSD. Parent advocates were also invited to "share their story" and present a parent perspective. Hospital specific and outpatient follow-up aggregate EHDI data was shared by EHDI staff. A "life of a child" scenario from birth through diagnosis, EI and family support was utilized allowing each partner to be recognized and share their specific role in a child's hearing health care. From this, professionals were able to ascertain a visual of the "networking" that occurs or needs to occur for each child. The "life of a child" scenario was tremendously impactful for all partners. Open discussions led to the identification of each community's hearing health care infrastructure, or lack thereof, additional program strengths and weaknesses with further discussions discerning strategies to overcome obstacles and barriers. Each visit also allowed ND EHDI and professionals to share educational information related to Joint Committee on Infant Hearing (JCIH) 1-3-6 recommendations. Community visits were very well received and have been missed statewide by community partners.

Addressing the need for hearing screen providers and all community stakeholders to become engaged and well versed in ND EHDI systems of care, JCIH recommendations, LTF/LTD, ND EHDI will reinstate community visits at ND's 12 birthing hospitals. ND EHDI will expand the scope of these visits to include educational materials and resources on the benefit of family-centered medical home and identify accurate, comprehensive up to date, evidence-based information that needs to be shared with families. Partners attending the visits will also be expanded to include the NDDoH SHS program, ND Newborn Screening (ND NBS) Program, a ND H&V GBYS Family Leader and NDFV representative to ensure providers are educated about additional resources available for families which in turn allows screening providers to educate the families they serve. ND EHDI via community visits will work to engage community and stakeholders and ensure their coordinated infrastructure includes meeting 1-3-6 recommendations, addressing LTF/LTD issues and increasing support for screening young children up to 3 years of age. Overall, partners meeting partners was proven to be a very effective strategy to enhancing partner collaboration and improving developmental outcomes of all infants and children in ND by increasing provider awareness/education through face-to-face discussions between community partners.

Objective 1.2: By March 2024, ND EHDI will reduce LTF/LTD and support a coordinated infrastructure to 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.

Activity 1.2.1: *Monitor statewide diagnostic outcome rates for areas of need and provide technical assistance/training to the audiology community.* ND EHDI staff will continue to promote complete, timely diagnostic assessments and documentation via weekly monitoring of outcomes reported in the OZ eSP system. ND EHDI's weekly analysis of documented and/or the lack of documented outcomes facilitates timely one-on-one TA/training and education to the individual facility or provider at the time of the identified issue(s). This directive will be continued as it has proven to effectively increase provider knowledge leading to the development and implementation of protocols/strategies by providers strengthening their internal infrastructure based on their individual issues. Furthermore, ND EHDI will incorporate additional training/educational opportunities for audiologists via secure video platforms such as ZOOM. This offers a hands-on guided approach to data entry into OZ eSP.

Activity 1.2.2: *Conduct community visits.* Addressing the need for audiologists to become well versed in ND EHDI systems of care, JCIH recommendations and reduce LTF/LTD, ND EHDI will reinstate community visits at ND's 12 birthing hospitals as referenced in Methodology, Activity 1.1.3.

Activity 1.2.3: *Work with state partners to explore methods to address barriers in timely diagnoses and reporting.* ND EHDI will seek the advice from the AC to identify additional strategies to overcome the lack of and need for complete audiological reporting. The parent voice is often more powerful than the professional voice. North Dakota EHDI will elicit family input from the FSOs to identify options and opportunities to share their parent perspective with the ND audiology community to promote early diagnosis and reporting, assuring appropriate family supports are initiated. ND EHDI will also survey ND Audiologists to identify additional strategies to increase audiological outcome reporting.

Objective 1.3: By March 2024, ND EHDI will reduce LTF/LTD and support a coordinated infrastructure to 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.

Activity 1.3.1: *Monitor statewide EI outcome rates for areas of need and provide technical assistance/training to EI service providers.* ND EHDI will continue to monitor EI data weekly and provide timely, one-on-one technical assistance to EI providers. Part C Developmental Disabilities Program Administrators/Managers (DDPA/DDPMs) are ND's EI single point of contact gatekeepers receiving the initial EI referral for services when a second stage hearing screen refer, or permanent hearing loss diagnosis occurs. Due to staff turnover and process changes, ND EHDI will also provide individual EI program trainings with Right Track, Part C, NDSD PIP and Tribal Tracking providers. The next step will be to provide each programs' Regional DDPA/DDPMs and providers with training/re-fresher training in the use of OZ eSP for complete documentation of outcomes and tracking of their individual follow-up efforts. Education will encompass JCIH recommendations including 1-3-6, the need for screening up to age 3 and additional resources available to families, e.g., DoH SHS Diagnostic/Treatment Program (financial support) and FSOs (ND H&V and FVND).

Activity 1.3.2: *Conduct community visits.* Addressing the need for EI providers to become well versed in ND EHDI systems of care and JCIH recommendations, ND EHDI will reinstate community visits at ND's birthing hospitals as referenced in Methodology, Activity 1.1.3. Community visits allow EI providers to learn, meet health care partners and educate partners about important role they play as a service provider of early intervention. They are in a unique position to assure families are educated and afforded statewide resources which reinforces the need for timely referral by partners to EI.

Activity 1.3.3: *Work with state partners to explore methods to reduce barriers in timely EI enrollment.* The ability for programs to seamlessly share information between programs is imperative to ensure the identification of infants and children with hearing loss and the ability to assure support for families. At present, ND EHDI and Part C are collaboratively working toward the development of a data sharing agreement with elicited expertise from the DaSy Center. The DaSy Center is a national TA center funded by the U.S. Department of Education, Office of Special Education Programs (OSEP). The strong relationship between ND EHDI and Part C has facilitated progress to meet this need. This will greatly expand the continuity of care between entities, allow for compliant communication between partners and increase the number of infants identified as DHH that are enrolled in EI services no later than 6 months of age. Additionally, ND EHDI will collaborate and explore methods to further enhance EI enrollment via community visits, trainings and TA discussions with the AC, ND audiologists, NDSD PIP and FSOs. Increasing the engagement of partners will not only lead to enhanced timely EI enrollment but also be inclusive of reducing LTF/LTD through the building of a sound EHDI partnered infrastructure.

Objective 1.4: By March 31, 2022, ND EHDI will develop a state plan with identified stakeholders to expand infrastructure, including data collection and reporting, for hearing screening for children up to age 3.

Activity 1.4.1: *Work with the AC, SHS/CYSHCN and FSOs to develop a state plan to expand infrastructure including data collection and reporting for children up to age 3.* ND EHDI will collaborate with the AC, NDDoH SHS/CYSHCN and FSOs utilizing a variety of modalities to

discuss and determine a plan of action for expanding the EHDI system of care beyond newborns to include young children up to the age of 3 in the EHDI Act 2017. These stakeholders bring diversified knowledge of the early childhood programs and can discern ways to expand our current infrastructure.

Activity 1.4.2: *Develop a list of current and potential partnerships for referral, training and information sharing.* With the assistance of current stakeholders, the ND EHDI team will identify and develop a comprehensive list of new partners to address referral, training and information sharing needs to reach children up to the age of 3.

Activity 1.4.3: *Assess gaps in data collection and reporting into the ND EHDI system.* The ND EHDI team will access gaps in data collection and reporting via OZ eSP documented outcomes. Additionally, ND EHDI will align with other health programs in ND, e.g., public health, county social services, Early Head Start programs to gain an understanding of the hearing care information collected by them and utilize it as a basis to address reporting gaps of children up to the age of 3.

Activity 1.4.4: *Provide education and training to current and new partners on the EHDI system and their role in expanding the infrastructure for hearing screening up to age 3.* Health programs identified as providers working with children up to the age of 3 will be assessed and provided with education/training to assure hearing screening occurs up to the age of 3. ND EHDI will also facilitate the reporting of hearing screen outcomes via online/fax-back reports.

Activity 1.4.5: *On an annual basis, update and reassess partners of the ND EHDI system.* ND EHDI will reassess and revise partnerships identified by gaps in reporting and services within each area of hearing health care to facilitate a statewide expanded coordinated infrastructure and accomplish program improvements.

Objective 1.5: By March 31, 2021 and annually thereafter, ND EHDI will assess, establish, maintain and improve partnerships for referral, training and information sharing.

Activity 1.5.1: *Assess gaps in referrals and information sharing.* The ND EHDI team will assess gaps in referrals and information sharing via OZ eSP documented outcomes. ND EHDI will collaborate with partners and implement efforts promoting stakeholder knowledge and education to elicit program improvements and sustainability.

Activity 1.5.2: *Develop a list of current and potential partnerships.* With the assistance of current stakeholders, the ND EHDI team will identify and develop a comprehensive list of new partners to address referral, training and information sharing needs to reach children for optimal developmental outcomes.

Activity 1.5.3: *Conduct trainings for current and new partners.* Through trainings, TA, community visits and expanded information sharing, ND EHDI staff will promote a statewide system of care to build upon collaborative efforts with current and new partners. Throughout the next grant cycle, ND EHDI proposes to focus efforts on: 1) increasing health professionals' and stakeholders' engagement within and knowledge of the EHDI system, 2) improving access and knowledge to EI providers and 3) improving family engagement, partnership, leadership and coordination of care services for families and children who are DHH within the ND EHDI system.

Activity 1.5.4: *Assess and develop methods of information sharing for state partners*. The ND EHDI program will facilitate engagement, outreach and education through community visits, national/state resources and family support educational opportunities. These activities will be a venue to provide knowledge of 1-3-6 recommendations, increase follow-up efforts and promote

referrals for continued services resulting in a decrease in LTF/LTD rates. Additionally, the method of information sharing is OZ eSP. ND EHDI's data system is the hub for ND EHDI coordination of care and the exchange of information. Often, a single provider may not be able to assure families are made aware of all supports available. For example, the provider may be limited on time, the family may not be ready to discuss/process the information or perhaps the provider is unaware of all resources. Partners referring to partners ensures families will be offered support during their journey and educated on the importance of complete timely follow-up, thus, reducing LTF/LTD.

Activity 1.5.5: *Annually, assess partnerships.* ND EHDI will reassess and revise partnerships and stakeholders to improve outreach education for referral, training and information sharing to health care professionals and service providers.

Objective 1.6: In October of each project year, ND EHDI will convene an EHDI advisory committee, comprised of at least 25 percent parents of children who are DHH or adults who are DHH, to advise on programs, objectives and strategies throughout the period of performance.

Activity 1.6.1: *Maintain and recruit a diverse and inclusive representation of AC members.* The AC is currently comprised of a diverse inclusive group of health care professionals and parents/family member that provide knowledge, expertise and experience obtained from within their career and/or life experiences. The ideas and advice generated from the AC is utilized to advise on programs, objectives and strategies throughout the period of performance. ND EHDI staff will continue to maintain, expand and recruit a diverse and inclusive AC.

Activity 1.6.2: *Work with ND FSOs to maintain and recruit a minimum of 25 percent AC members who are parents of children who are DHH and/or adults who are DHH.* ND EHDI will collaborate with EI programs and FSOs (ND H&V, FVND) to identify and recruit a minimum of 25% of AC participants who are parents/families of DHH and/or adults who are DHH.

Activity 1.6.3: *Schedule and conduct at least one AC meeting on an annual basis.* The AC will meet a minimum of one time per year with additional subcommittee meetings occurring as needs present. Meetings would be best accomplished in a face-to-face setting however, due to distance and time constraints for professionals/families and the lack of funding to support travel, distance technologies through a reliable cloud platform for video and audio conferencing will be employed to elicit participation.

Objective 1.7: By March 31, 2022, a plan will be developed to address diversity and inclusion in the EHDI system.

Activity 1.7.1: *Explore methods to address diversity and inclusion within the ND EHDI system.* ND EHDI is located at the NDCPD on the Minot State University (MSU) campus. Through NDCPD, ND EHDI staff have access to trainings and resources in cultural and linguistic competency via URLEND didactic training on cultural competency, AUCD's multicultural toolkit and NDCPD's Cultural Competency Advisory Committee (CCAC). Our current resources foster diverse relationships, strengthen community connections with professionals and families. Collectively, these resources allow ND EHDI to be engaged in efforts to be culturally and linguistically responsive to populations across ND. ND EHDI will continue to assess and explore ways to address and enhance diversity and inclusion in the ND EHDI system.

Activity 1.7.2: *Collaborate with state partners to develop a plan to address diversity and inclusion.* The ND EHDI team will collaborate with the AC and FSOs to develop a plan addressing diversity and inclusion. Initial discussions will occur at the AC meeting and/or FSOs

meetings with subcommittees being developed to further identify needs and strategies addressing the development of a plan.

Objective 1.8: Throughout the four-year project period, ND EHDI will implement quality improvement activities to monitor and assess program performance in the areas of **provider outreach and education** and **family engagement and family support** and disseminate findings in an annual report.

Activity 1.8.1: *Promote Quality Improvement (QI) methods to address unique needs of the ND EHDI system of care within chosen program performance areas.* ND EHDI has chosen two area of focus: **provider outreach and education** and **family engagement and family support**. ND EHDI will collaborate with partners to utilize QI methods in establishing a means of improving the EHDI system of care. For *provider outreach and education partners,* ND EHDI will collaborate with the NDDoH (SHS and NBS) programs, the North Dakota Human Services (NDHS) and the NDSD. For *family engagement and family support*, the second area of focus, ND EHDI will collaborate with FSOs (ND H&V, FVND).

Activity 1.8.2: *Provide technical assistance for QI activities.* North Dakota EHDI will assist partners in the utilization of evidence-based QI methodologies (Plan Do Study Act) by providing ongoing TA and support. Identified partners and stakeholders will be asked to determine goals, methods and timelines for improvement which will support an increase in diversity and community EHDI system capacity while strengthening a process for comprehensive and evidence-based information sharing.

Activity 1.8.3: *Disseminate QI progress via an annual report.* ND EHDI staff through regular communications and TA with the identified partners, will report findings on the progress of the QI initiatives.

Objective 1.9: Throughout the project period, ND EHDI will maintain, improve and promote an accessible and culturally appropriate website that encompasses accurate, comprehensive and evidence-based information.

Activity 1.9.1: *Examine the current ND EHDI website for necessary updates and implement enhancements as needed.* The EHDI staff, FSOs and the AC will examine the ND EHDI website for user-friendliness, gaps and needs. Updates to the website will be completed by ND EHDI staff to assure the website includes accurate, comprehensive, evidence-based information in a format that is accessible and inclusive.

Activity 1.9.2: *Regularly monitor and implement necessary updates to information on the ND EHDI website.* A ND EHDI staff member will be assigned to maintain and improve the existing ND EHDI website to assure it is accessible, culturally appropriate and offers accurate, comprehensive and evidence-based information.

Activity 1.9.3: *Collaborate with EHDI partners to promote the ND EHDI website.* EHDI partners/stakeholders have been a great resource to share content on multimedia platforms to improve provider outreach, education, engagement and family support. ND EHDI will continue to collaborate with partners and stakeholders to expand current efforts of public awareness of the ND EHDI website via links from their unique multimedia social platforms, e.g., Twitter, Facebook, Instagram.

Objective 1.10: Throughout the project period, ND EHDI will work with key stakeholders to develop a sustainability plan to be completed by March 31, 2024.

Activity 1.10.1: *Collaborate the AC to discuss sustainability and the need for a plan.* There is a need to enlist the AC and other EHDI stakeholders in the process of developing a written sustainability plan to maintain key elements, e.g., website, services and intervention. The ND EHDI program will engage the AC to explore the sustainability of an EHDI system of care and develop a written plan through a coordinated planning process. The ND EHDI program will facilitate the development of a sub-committee, regular meetings and continual AC input throughout the planning process.

Goal 2: Engage, educate and train health professionals and service providers in the EHDI system.

Objective 2.1: By March 2024, ND EHDI will have conducted outreach and education to health professionals and service providers by hosting 12 community visits to address 1-3-6 recommendations, screening, diagnosis and intervention needs up to age 3, patient/family-centered medical home (PFCMH) and the importance of relaying current and accurate unbiased information to families.

Activity 2.1.1*: Conduct outreach and education by coordinating 12 community visits.* Building a successful statewide EHDI system requires personal connections and building relationships. The ND EHDI team will collaborate with family leaders to conduct face-to-face community visits to address key elements to ensure that children who are DHH are identified through newborn, infant and early childhood hearing screening and receive diagnosis and appropriate EI to optimize language, literacy, cognitive, social and emotional development.

Activity 2.1.2: *Promote QI methods to address individual community gaps and needs.* During community visits, ND EHDI staff will educate on and promote the use of QI methods to support system changes. The ND EHDI staff will work with communities providing TA for the engagement of QI activities.

Objective 2.2: Throughout the project period, ND EHDI will collaborate with state and federal EHDI-partners to provide education and training opportunities on program specific information to health professionals, service providers and FSOs via various platforms.

Activity 2.2.1: *Promote the use of educational offerings by federal and state EHDI partners to ND professionals and service providers as a means of continued education.* Our federal and state EHDI partners offer many evidence-based educational opportunities. Partners include Utah Regional Leadership Education in Neurodevelopment and related Disabilities (URLEND) didactic training on cultural competence, AUCD's multicultural toolkit, MCHB PFCMH, National Technical Resource Center/National Center for Hearing Assessment and Management (NTRC/NCHAM), FL3, NDDoH, ND FSOs. The ND EHDI staff will promote opportunities through community visits, quarterly newsletters, social media (Facebook and Twitter), email, ND EHDI website and stakeholder/partners multimedia platforms.

Activity 2.2.2: *Promote participation in URLEND opportunities to ND EHDI stakeholders.* ND EHDI will collaborate and promote the URLEND efforts to coordinate and offer learning opportunities for ND EHDI Stakeholders. Typically, in past years, URLEND sessions presented at the NDCPD at MSU has offered at least two sessions directed toward hearing health care to support continuing education and professional development to individuals with disabilities, family members and support professionals. Professionals and families will be afforded these opportunities at no cost. Sessions are typically offered via Polycom have been save and shared on ND EHDI multi-media platforms for greater accessibility and outreach.

Objective 2.3: Annually, ND EHDI will increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.
Activity 2.3.1: *Conduct community visits.* The proposed ND EHDI 12 community visits will actively connect diverse rural communities in an inclusive effort by sharing resources, expertise and opportunities to inform and educate best care practices. The community visits will bring together a broad mix of community members to create partnerships and tailored work plans for long-term local success. Each community visit will prioritize and choose strategic goals and vision for their community.
Activity 2.3.2: *Provide monthly multi-media educational opportunities for health care professionals and service providers.* The ND EHDI national and state partners (FSOs, NDDoH URLEND, PFCMH, NTRC, FL3) have multiple professional education, evidence-based information sharing opportunities. The opportunities will be shared through EHDI multi-media platforms, quarterly ND EHDI newsletters, email and community visits.
Activity 2.3.3*: Produce 12 issue briefs focused on key aspects of the EHDI program.* ND EHDI team will collaborate with stakeholders to create 12 issue briefs for ND health professions on culturally appropriate, accurate, comprehensive, evidence-based on key aspects to offer insight and education of the EHDI system.
Activity 2.3.4: *Disseminate a statewide quarterly newsletter to state stakeholders.* ND EHDI will continue to collaborate and partner with ND EHDI stakeholders to participate in the content and dissemination of the quarterly newsletter. The newsletter will address diversity inclusion with a focus on key aspects of the EHDI system.

FAMILY ENGAGEMENT AND EARLY CHILDHOOD COORDINATION

Goal 3: Strengthen capacity to provide family support and engage families with children who are DHH as well adults who are DHH throughout the EHDI system.
Objective 3.1: By March 2024, ND EHDI will conduct outreach and education engaging families throughout all aspects of the ND EHDI program, involving family partners in the development, implementation and evaluation of the EHDI Program.
Activity 3.1.1: *Recruit at least 25% families of DHH individuals or individuals themselves who are DHH to participate in the AC.* The AC is currently comprised of a diverse inclusive group of family members that provide knowledge and expertise obtained from their life experiences. ND EHDI will collaborate with EI programs and FSOs (ND H&V, FVND) to identify and recruit a minimum of 25% of AC participants who are parents/families of DHH and/or DHH individuals.
Activity 3.1.2: *Provide education on EHDI topics through monthly webinars via Zoom or other web-based platforms.* ND EHDI will collaborate with partners NDDoH (SHS and NBS) and contracted FSOs to provide education on EHDI topics through monthly webinars to establish a means of improving the EHDI system of care. Identified stakeholders will be asked to identify goals, methods and timelines for improvements that will support and increase the capacity of each other's trainings and educational information to strengthen the diversity and comprehensive evidence-based information. This will provide another resource to strengthen the capacity of family engagement.
Activity 3.1.3: *Provide leadership opportunities involving different roles within the EHDI system.* ND EHDI, in collaboration with FSOs, will provide families with opportunities for engagement and leadership within the ND EHDI program and system. Additionally, ND's FSOs

provide leadership opportunities through federal partners to participate via webinars, training opportunities and mentorship experiences.
Activity 3.1.4: *Work with family leaders to educate and participate in community visits.* Family leaders, identified in collaboration with FSOs, will engage in dialogue during community visit to share parent perspective, parents' hopes, aspirations for their child, their sense of what the child needs and suggestions about ways stakeholders can help improve the ND EHDI system.
Activity 3.1.5: *Participate in the development of the quarterly ND EHDI Newsletter.* The FSOs have been a great resource to share content for the ND EHDI newsletter. The FSOs will maintain and expand their content for the ND EHDI newsletter which will strengthen family support and engage families within the ND EHDI system and serve as a conduit where the family voice can be heard.
Activity 3.1.6: *Support one family leader to attend the Annual Early Hearing Detection and Intervention (EHDI) Meeting.* The ND EHDI staff will work together with FSOs to identify and fiscally support a ND parent of a child who is DHH to attend the annual national EHDI conference.

Objective 3.2: By March 2024, ND EHDI will facilitate partnerships among families, health care professionals and service providers through 12 community visits conducted throughout North Dakota to ensure that providers understand the best strategies to engage families.
Activity 3.2.1: *Engage family leaders to participate in and present at community visits.* To ensure providers understand the best strategies to engage families in the EHDI system of care, the ND EHDI program will enlist family leaders in an active role in community visits. A parent perspective will guide discussion on how providers can engage families. Through this experience, families will also become aware of how they can be effective partners in the ND EHDI process.

Objective 3.3: Annually, ND EHDI will use the **25% of funding dedicated to family engagement and family support** activities to support an ***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.
Activity 3.3.1: *Develop a contract and fund two ND FSOs supporting engagement of family-to-family support services.* North Dakota EHDI will develop a contract to 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. ND EHDI will also provide fiscal support to two ND FSOs totaling 25% of the funding from HRSA. The FSOs will be responsible for providing quarterly reports to ND EHDI.
Activity 3.3.2: *Continue to fund the ND H&V Guide by Your Side family support program.* The ND EHDI program will provide fiscal support to the ND GBYS program. The GBYS program provides emotional support and unbiased information delivered by trained Parent Guides to other families. This support is especially powerful because it is provided by parents who can relate through their own lived experiences of DHH and system of care navigation. The GBYS guides will be an impactful enhancement to community visits. It is anticipated they will be a key component of change and progress within the ND EHDI system.

Objective 3.4: Annually, ND EHDI will use **25% of funding dedicated to family engagement and family support** activities which will support an ***increase by 10 percent*** the number of families ***enrolled in DHH adult-to-family support services*** by no later than 9 months of age.
Activity 3.4.1: *Collaborate with the contracted FSOs to identify programs and activities that provide direct DHH adult consumer-to-family support services.* The FSOs and ND EHDI will collaborate to identify and develop a comprehensive list of programs and activities that provide direct DHH adult consumer-to-family support services.
Activity 3.4.2: *Collaborate with FSOs to survey families on the need for a formally organized program offering adult-to-family support services.* ND EHDI and FSOs will collaborate to develop a survey. The FSOs will share the survey link to engage families with children who are DHH regarding the need for a formally organized program offering adult-to-family support services. ND EHDI will review the survey data to determine the need for identifying additional strategies.

Objective 3.5: Through March 31, 2024, ND EHDI will consult with the HRSA-20-051 recipient, the Family Leadership in Language and Learning (**FL3 Center**), for resources, TA, training, education, QI and evaluation to strengthen the infrastructure and capacity for family engagement and family support in the state.
Activity 3.5.1: *Consult with the FL3 Center to determine available resources, TA, training, education, QI and evaluation.* ND EHDI will consult with the FL3 for research-based concepts to support families, parents and caregivers of infants/children who are DHH and identified through newborn hearing screening.
Activity 3.5.2: *The FSOs and ND EHDI will promote resources, TA, training, education, QI and evaluation as they are made available through the FL3 to families in ND.* The FSOs and ND EHDI will continue collaborate with FL3 to promote FL3 resources to strengthen the infrastructure and capacity of the ND EHDI system which will expand current efforts of public awareness and promote the EHDI system of care.

Goal 4: Facilitate improved coordination of care and services for families and children who are DHH
Objective 4.1: By March 31, 2021, ND EHDI will have assessed and developed a plan to addresses coordination across early childhood programs to improve services.
Activity 4.1.1: *Coordinate a team comprised of members from the AC, FSOs, ND EHDI staff and other identified partners to focus on the assessment of coordination of care and services across early childhood programs.* The ND EHDI team will work with current partners to identify key stakeholders to participate in the assessment of coordination of care and services across early childhood programs.
Activity 4.1.2*: In collaboration with "team members" develop a plan to address improvement of coordination of care and services among early childhood programs.* The ND EHDI program will gather perspectives and information from multiple disciplines and entities to improve the ND EHDI system of care so families with newborns, infants and young children up to 3 years of age who are DHH receive appropriate and timely services. Methodologies such as surveys and community visit group feedback will be solicited.

Objective 4.2: By March 31, 2023, ND EHDI will demonstrate evidence of improvement in communication, training, referrals, data sharing, etc. through meeting minutes and data reports.

Activity 4.2.1: *Initiate meetings to discuss and identify coordination of care service needs with early childhood programs in ND.* The ND EHDI program will coordinate meetings with new and current early childhood providers to promote improved communication, training, referrals and data sharing. During meetings, discussion will help identify barriers and determine goals that can improve coordination of care within the EHDI system.
Activity 4.2.2: *Provide education and training on the EHDI system of care, referral practices and information sharing.* ND EHDI will provide trainings and TA to early childhood program partners. ND EHDI staff will provide education and training through face-to-face community visits, webinars, newsletters, article briefs, TA, social media, etc. The ND EHDI program will also collaborate with federal and state EHDI stakeholders to expand outreach and educational opportunities.

COLLABORATION

Goal 5: Collaborate with national resources to support initiatives for the enhancement of the EHDI system of care in North Dakota.
Objective 5.1: On an annual basis, one or two EHDI staff and one family leader will participate in the Annual Early Hearing Detection and Intervention (EHDI) Meeting.
Activity 5.1.1: *One to two ND EHDI staff members will be identified to attend the annual EHDI national meeting during the project period.* One to two ND EHDI staff will attend the national conference providing them the opportunity to develop networks, obtain program improvement ideas, increase awareness and knowledge of EHDI system best practices.
Activity 5.1.2: *ND EHDI will identify and support one ND parent leader to attend the annual national EHDI conference during the project period.* As required by the NOFO, ND EHDI will support attendance of one family member of a child who is DHH at the national annual EHDI conference. A ND family expressed how important it was for them to attend the 2019 EHDI conference in Chicago *"I was blessed with the amazing opportunity to attend the 2019 EHDI conference in Chicago... My husband and I walked in tentative about what steps to take next for our son and we left feeling empowered, informed and ready to tackle the journey ahead. Just seeing so many professionals and families that are passionate about positive change, furthering research and creating a better tomorrow for people like my son, filled us with hope… The realization that we are not alone on this journey renewed our strength and vigor to keep going! Thank you for this amazing opportunity, it was invaluable to me and my family." T.Devlin, ND Parent*

Objective 5.2: On a quarterly basis, utilize the FL3 Center, URLEND, NTRC/NCHAM and National Resource Center for PFCMH to implement various initiatives.
Activity 5.2.1: *Collaborate with the Utah Regional Leadership Education in Neurodevelopment and Related Disabilities (URLEND) effort to coordinate and offer learning opportunities for ND EHDI Stakeholders.* The URLEND sessions are presented at the NDCPD at Minot State University. At least two sessions are directed toward hearing health care. Professionals and families will be afforded these opportunities at no cost. Sessions are typically offered via Polycom and the sessions are recorded and shared on ND EHDI multi-media platforms to increase education opportunity.
Activity 5.2.2: *ND EHDI will promote various opportunities for information and education throughout ND, as offered by federal partners.* Through quarterly newsletters, multi-media

formats and email, the ND EHDI team will continue to inform and promote educational opportunities from our federal partners.

WORK PLAN

The Work Plan, located in attachment 1, provides the structure ND EHDI will follow and serves as a guide for timelines, expected outcomes, sources utilized to measure progress and responsible staff and partners. The details of the work plan are incorporated within the Methodology section of the proposal.

RESOLUTION OF CHALLENGES

The ND EHDI program is fully aware of the various challenges that can accompany engaging stakeholders to develop and implement an EHDI system of care. North Dakota EHDI recognizes that the platform on which EHDI was built must be maintained. It will remain vital to continue documenting all births as well as maintain and promote follow-up as these efforts are critical for laying the foundation for a strong EHDI program.

The challenges listed below are the result of analyses of the Needs section of this proposal.

Challenge 1: *Reduction in annual funding amounts***.** The reduction of funding amount on an annual basis will have an impact on direct supports provided by ND EHDI staff. The need to conduct community visits is imperative to enhancing reporting efforts and engagement within the ND EHDI system. Staff time will be impacted by the reduction of funding and the redirection of 25% of the funded amount. In order to alleviate this burden and continue moving forward and showing progress, ND EHDI will initiate the following resolutions:
Resolution 1a: Work with state partners to determine activities that can be carried out without a duplication of efforts. This will promote accountability and collaboration of coordinated care.
Resolution 1b: Work with partners to identify funding support options for the ND EHDI system.
Resolution 1c: Reduce staff time identified through efficiencies in resolution 1a. to support community visits and other activities anticipated to have the most impact with promising outcomes.

Challenge 2: *Reduced ND EHDI staff FTE rates.* The reduction in ND EHDI staff FTE rates will hinder time allowance for addressing new areas of focus while maintaining LTF/LTD and promoting ND EHDI initiatives. Staff reductions are attributed to the allotment of 25% of available funds being allocated to a FSOs and a decrease in annual funding. ND EHDI is solely funded by CDC and HRSA EHDI. ND state appropriated funds **do not** support ND EHDI staff and activities.

Resolution 2a: ND EHDI staff will alter current follow-up methods by streamlining the in-depth nature of practices to allow time to address new areas of focus.
Resolution 2b: ND EHDI will promote provider-initiated follow-up. Strategies will be implemented to promote and engage provider self-reliance and sustainability to promote maintenance and reduction of LTF/LTD.

Resolution 2c: ND EHDI will promote the utilization of technology such as Telepathy to alleviate LTF/LTD.
Resolution 2d: ND EHDI will work with the FSOs to impress upon health professionals and service providers the importance of complete, consistent and timely reporting to the ND EHDI program.
Resolution 2e: Staff will work with the ND audiology community to promote timely self-directed reporting, referrals to service providers and adherence to the 1-3-6 recommendations.

Challenge 3: *Maintaining timely, complete, accurate OZ eSP data.* ND EHDI utilizes OZ eSP as the online reporting system for hearing health care reporting throughout ND. The system gives users access for data reporting, viewing of records (for whom they provide services) and case notes. At present, all birthing hospital nurseries, many audiologists and EI programs including Right Track, Part C, Tribal Tracking, the PIP and family support service providers have access to the OZ eSP online data system. System updates and staff turnover have proven to be challenging in assuring the data entered is timely, complete and accurate.

Resolution 3a: To address system updates and staff turnover, ND EHDI will continue to provide trainings and TA.
Resolution 3b: To increase timeliness and accuracy of reported data, ND EHDI staff will continue collaborative efforts with birthing hospitals utilizing manual result entry methods to implement OZ eSP's Telepathy functionality. Telepathy allows for imports of hearing screening results to be uploaded into OZ eSP.
Resolution 3c: ND EHDI will provide TA and training to EI providers to assure the reporting of timely, complete and accurate data.

Challenge 4: *Continued maintenance of LTF/LTD reductions.* With the proposed ND EHDI staff reductions in time and budget constraints, ND EHDI is concerned about increases in the LTF/LTD rate. Presently, ND EHDI Follow-up Coordinators dedicate a significant amount of their workload to ensure timely follow-up is complete. This includes tracking every infant in ND to assure post hospital discharges with recommended follow-up appointments are scheduled and attended. If appointments are not reported in the OZ eSP system, ND EHDI staff contacts the hospital to determine appointment status. If appointments appear missed and/or not attended, ND EHDI staff contact the hospital to see if the appointment was truly missed and if it can be rescheduled. If an appointment was completed but the results are not updated in OZ, staff request hospital providers or audiologists to update results. If infants do not complete follow-up appointments, ND EHDI staff contacted hearing care providers and/or families to support follow-up efforts. Staff also provide frequent lists of infants with incomplete hearing care to providers to promote follow-up. Reminder letters are sent to families of infants who do not have documented complete follow-up care. The letters include educational information, resources for services and EI options to promote follow-up and were proven to be effective through a previous QI project.

ND EHDI has struggled to obtain audiological documentation of outcomes. Some audiologists have indicated they are too busy, others indicate they do not know how to enter results in OZ eSP and some are just unwilling to share results.

Resolution 4a: ND EHDI will engage EHDI service providers in the development of ideas and strategies to address LTF/LTD.
Resolution 4b: Through collaborative partnerships of agencies within the NDDoH, ND EHDI will utilize existing NDDoH practices to promote follow-up efforts. The division of Special Health Services has funding available for families whose infant did not pass the birth hearing screen or who have been identified with a hearing loss; however, many hearing care partners and families are unaware of this service. ND EHDI will promote the availability of funding to health care partners and EI providers.
Resolution 4c: Birthing hospitals will be educated and trained on the need to provide a referral to the pre-Part C program (Right Track) for infants receiving a second stage referral outcome. At present, referrals to Right Track are primarily added to OZ eSP by ND EHDI staff. Once hospitals are adding the Right Track referrals, ND EHDI will continue to monitor their progress to assure all referrals are entered in OZ eSP in a timely, consistent manner. Hospital referral to Right Track promotes timeliness for follow-up through education and support offered to families.
Resolution 4d: Community visits will work to assure partners are educated in 1-3-6 practices and the availability of family supports. “EHDI system knowledgeable” providers will be able to educate families and know how to connect families to hearing care supports. Partners to receive education will include health care providers (hospital nursery staff, primary care physicians, audiologists, ENTs), EI and family support service providers. Opportunities for education of health care partners and families will also be promoted through URLEND sessions as well as social media and webpages from ND EHDI and providers.
Resolution 4e: ND EHDI will elicit solutions during community visits to promote audiological data entry. Involving community partners in these processes might be better received when education and information of data entry importance comes from medical professionals and family members.
Resolution 4f: ND EHDI will engage family leaders in community visits. The consumer perspective from the family leaders will provide support in the importance of coordinated care efforts via reporting of information.

Challenge 5: *Addressing Sustainability.* Sustainability has proven difficult for the ND EHDI program. It’s important to go through the process of developing a written plan to address sustainability and engage ND EHDI state partners and family leaders.

Resolution 5a: Engage the ND EHDI AC and family leaders in addressing sustainability solutions in ND for an EHDI system of care.
Resolution 5b: Form a smaller sustainability committee to allow for a manageable number of participants to conduct meetings and keep the topic of ND EHDI sustainability moving forward to a larger group of stakeholders.
Resolution 5c: Compile and develop an organized and written approach to addressing sustainability to guide sustainability plans.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Plan for Program Performance Evaluation

Introduction: The principal goal for ND EHDI is to "*ensure that children who are DHH are identified through newborn, infant and early childhood hearing screening and receive diagnosis and appropriate EI to optimize language, literacy, cognitive, social and emotional development."* ND EHDI's evaluation plan was designed to efficiently utilize inputs and key processes to monitor and measure progress toward the goals and objectives of the project. The plan incorporates activities to ensure achieving expected outcomes of an increase in health professional and service provider education where all newborns complete the hearing screening process, receive timely diagnosis, enroll in EI and have an increase in family support services. Once diagnosed, families have a greater opportunity to receive coordinated care, enrollment in EI programs and family support. Specifically, the plan will lead to the following ***expected outcomes*** of: ***1) 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.; 2) 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.; 3) 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.; 4) 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.; 5) Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age and; 6) Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.***

ND EHDI program staff will monitor ongoing processes and progress through the ND EHDI Information System (ND EHDI-IS) called OZ eSP (Attachment 2: Staffing Plan and Job Descriptions for Key Personnel). Health care professionals and service providers have access to OZ eSP for data entry of screening, diagnosis, EI and family support progress as well as provider referrals. ND EHDI staff monitor the information system daily to track and promote continued follow-up, referral and enrollment activity. Several activities conducted by ND EHDI staff in collaboration with stakeholders and bordering state partners, will contribute to the progress of achieving expected outcomes.

Program Evaluation Process: The evaluation of ND EHDI program effectiveness has most consistently been completed through the analyzing of data collection efforts. Educating and engaging reporting sources are key contributors to positive program performance expressed through data collection outcomes. The expected outcomes of the HRSA directed objectives one through six will drive the activities and guide the measurement of performance. Together, they will assist the ND EHDI program in evaluating the level of achievement and overall program progress. The ND EHDI program will continually assess effectiveness and provide interventions to support state health care professionals and service providers in their efforts to enhance a comprehensive ND EHDI system of care. The ND EHDI Logic Model (Attachment 1: Work Plan and Logic Model) provides a visual reference on how inputs contribute to the processes, expected outcomes and overarching goal.

Program Evaluation Team/Key Personnel:

Table 1. Key Evaluation and Technical Support Personnel		
Key Personnel	**Key Processes**	**Responsibilities**
Jerusha Olthoff (Project Director)	• Data collection • Data Analysis • Community coordination facilitator • Educate/Train on EHDI system	• Program Management • Oversight of evaluation activities to ensure all evaluations are conducted as planned • Coordinate/Facilitate meetings • Analyze quantitative data • Complete reports
Sue Routledge (Data/Follow-Up Coordinator)	• Data collection • Data Analysis • Community coordination facilitator • Educate/Train on EHDI system	• Gather, review, analyze quantitative data • Promote follow-up • Coordinate the analysis of qualitative data • Ensure implementation of findings • Coordinate data collection with community members
Christine Brigden (Data/Follow-Up Coordinator)	• Data collection • Data Analysis • Community coordination facilitator • Educate/Train on EHDI system	• Gather, review, analyze quantitative data • Promote follow-up • Coordinate the analysis of qualitative data • Ensure implementation of findings • Coordinate data collection with community members

The formulas shown below in the *"Performance Measurement Plan"* indicate how ND EHDI will determine achievement of long-term outcome measures for screening, diagnosis, EI, family support and trained health professionals/service providers. All performance measures will be collected through OZ eSP. The ND EHDI team as well as collaborative partners will engage and train key program partners/reporting sources throughout the project period via Zoom meetings, TA phone calls, community visits and one-on-one trainings. Health care professionals and service providers have direct access to OZ eSP for the collection of data and promotion of coordinated care.

Measures to Assess Performance Progress: ND EHDI will utilize the 2017 Centers for Disease Control (CDC) data analyzed and reported for the EHDI Hearing Screening and Follow-up Survey (HSFS) to establish baseline data for evaluation activities and progress measurement. Targets are determined by six primary HRSA driven area indicators of performance. The performance areas are divided into six groups: 1) Screening; 2) Diagnosis; 3) Enrollment in EI; 4) Family-to-Family Support 5) Adult-to-Family Support; and 6) Trained Health Professional and Service Providers. The ability to **obtain and report data** from the ND EHDI Information System, OZ eSP, is accomplished by providing access, education, technical assistance, monitoring and feedback to reporting sources.

Objective Performance Measures

1) Screening *no later than 1 month of age*

Approach/Objective: By March 2024, 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.

Formula: # Screened for Hearing Loss (no later than 1 month of age) / # Total Occurrent Births Reported to ND EHDI Program * 100
Baseline: Screening rate based on 2017 HSFS = **97.8%**
Target: ***Increase by 1 percent from baseline per year***, or achieve at least a 95 percent screening rate (2021 = 98.9%, 2022 = 99.9%, 2023 = 100%, 2024 = 100%)
Numerator: # Screened for hearing loss (# Total pass <30 days of age + # Total refer <30 days)
Denominator: # Total live births reported to ND EHDI for reporting year.
Numerator: 11844 + 268
Denominator: 12388
(11844 + 268) / 12388 * 100 = 97.8%
Data Collection/Reporting Method: OZ eSP

2) <u>Diagnosis</u> *no later than 3 months of age*
Approach/Objective: By March 2024, 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.
Formula: # Total Diagnosed Before 3 Months of Age / # Total Not Pass * 100
Baseline: Diagnostic rate based on 2017 HSFS = **14.2%**
Target: Increase by 10 percent from baseline, or ***achieve a minimum rate of 85 percent*** (2024 = 85%)
Numerator: # Total diagnosed before 3 months of age (# No hearing loss <3 months of age + # Permanent hearing loss <3 months of age)
Denominator: Total not pass most recent/final screen.
Numerator: 29 + 11
Denominator: 282
(29 + 11) / 282 * 100 = 14.2%
Data Collection/Reporting Method: OZ eSP, fax back form, online reporting form, ND EHDI Follow-up

3) <u>EI Enrollment</u> *no later than 6 months of age for those diagnosed DHH*
Approach/Objective: By March 2014, 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.
Formula: # Total Enrolled in EI before 6 months of age (Part C and Non-Part C) / # Total Enrolled in EI (Part C and Non-Part C) * 100
Baseline: Enrolled in EI based on 2017 HSFS= **62.5%**
Target: Increase by 15 percent from baseline, or ***achieve a minimum rate of 80 percent*** (2024 = 80%)
Numerator: # Total Enrolled in EI before 6 months of age (Part C and Non-Part C)
Denominator: # Total Enrolled in EI (Part C and Non-Part C)
Numerator: 9 + 1
Denominator: 13 +3
(10 / 16) * 100 = 62.5%
Data Collection/Reporting Method: OZ eSP, collaboration with EI providers

4) <u>Family-to-Family (F2F) Support</u> *no later than 6 months of age for those diagnosed DHH*
Approach/Objective: By March 2024, 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.
Formula: # Total enrolled in F2F prior to 6 months of age in 2024 / # Baseline * 100
Baseline: # Families enrolled in F2F by no later than 6 months of age (April 1, 2020 - March 31, 2021) = To Be Determined (TBD)
Target: ***Increase by 20 percent from TBD baseline by 2024***
Numerator: # Total enrolled in F2F support prior to 6 months of age in 2024
Denominator: # Baseline
Numerator: TBD
Denominator: TBD
Data Collection/Reporting Method: OZ eSP, collaboration with F2F support organizations

5) <u>Adult-to-*Family* *Support*** *no later than 9 months of age for those diagnosed DHH*
Approach/Objective: By March 2024, using data collected from year 1 as baseline data, increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.
Formula: # Total enrolled in DHH adult-to-family support services by no later than 9 months of age in 2024 / # Baseline * 100
Baseline: # Families enrolled in DHH adult-to-family support services by no later than 9 months (April 1, 2020 - March 31, 2021) = To Be Determined (TBD)
Target: ***Increase by 10 percent the number of families enrolled by 2024***
Numerator: # Total enrolled in DHH adult-to-family support services by no later than 9 months of age in 2024
Denominator: # Baseline
Numerator: TBD
Denominator: TBD
Data Collection/Reporting Method: OZ eSP, collaboration with F2F support organizations

6) <u>Trained Health Professionals and Service Providers</u>
Approach/Objective*:* By March 2024, using data collected from year 1 as baseline data**,** **i**ncrease by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.
Formula: # Total health professionals and service providers trained on key aspects of EHDI Program by 2024/ # Baseline * 100
Baseline*:* # health professionals and service providers trained on key aspect of the EHDI Program (April 1, 2020 - March 31, 2021) = To Be Determined (TBD)
Target: Increase by 10 percent number of trained on key aspects of the EHDI Program by 2024
Numerator: # Total health professionals and service providers trained on key aspects of EHDI Program by 2024
Denominator: # Baseline
Numerator: TBD
Denominator: TBD

Data Collection/Reporting Method: # of attendees at training events, # of participants in webinars/calls, # reported by partnering programs

Organization Systems and Processes that support ND EHDI Performance Management-

Partners: The ND EHDI program is fortunate to have supports from both federal and state partners. The National Center for Hearing Assessment and Management (NCHAM) and the Family Leadership in Language & Learning (FL3) are utilized by ND EHDI for guidance and education on variety of EHDI topics. ND EHDI has established and maintained a network of voluntary based and/or memorandum of understanding (MOU) driven partnerships with ND's hearing health care providers and vested hearing health support programs that support the effective tracking of performance outcomes. Partners have included but are not limited to all birthing hospitals, ND's American Academy of Audiologists (NDAAA), American Academy of Pediatrics (AAP), North Dakota School for the Deaf (NDSD), the state's EI programs (Right Track and Part C programs), Tribal Tracking, the Parent Infant Program (PIP) and public health units. Collaborative efforts also include multiple divisions under the North Dakota Department of Health (NDDoH) including Vital Records, Maternal Child Health (MCH), Title V Children and Youth with Special Health Care Needs (CYSHCN) program/ Special Health Services (SHS), the Newborn Screening Program (NBS) and North Dakota Hands & Voices and Family Voices of North Dakota (ND H&V, FVND). Partnering with these programs provides ND EHDI with the support necessary to continue the work of incorporating QI best practice processes within the EHDI system of care.

Data Collection and Management: Data collection and management is accomplished via a web-based platform (OZ eSP from OZ Systems, Inc.). ND EHDI staff are responsible for educating and training reporting sources on data reporting standards that support a quality EHDI system of care in ND. Collected data are analyzed by ND EHDI staff and utilized to determine baselines/targets and to report on performance measures for annual progress reports.

Current Staff Experience, Skills and Knowledge: Both HRSA and CDC funded ND EHDI projects have been carried out through the NDCPD UCEDD for the past 19 years, on the behalf of the NDDoH. Two of the current staff have been with the ND EHDI program for fourteen of the nineteen years. ND EHDI has trained, implemented and provided TA for ND EHDI's web-based data system (OZ eSP). Throughout the years, staff have developed relationships with EHDI stakeholders throughout ND, streamlined reporting practices, promoted and helped implement EHDI best-practices in ND, participated in annual EHDI conferences, worked with other state EHDI program staff on border baby issues, collaborated with ND FSOs and educated and informed ND residents on the importance of EHDI. The combined experiences and knowledge of current ND EHDI staff is identifiable by the ND EHDI program's continued progress including systems changes, new collaborations and reporting efforts.

The ND EHDI Coordinator is the NDDoH Newborn Screening Program (NBS) Director. ND EHDI is staffed by 3 personnel: .50 Full Time Equivalent (FTE) Project Director, a .70 FTE Data/Follow-up Coordinator and a .50 FTE Follow-up Coordinator (Attachment 2: Staffing Plan and Job Description for Key Personnel).

Joyal Meyer, ND EHDI Coordinator, is the Newborn Screening Director for the Special Health Services division within the NDDoH. She obtained her bachelor's degree in Nursing from Medcenter One College of Nursing and her master's in nursing administration from the University of Mary in 2012. In her role as a Program Director within the ND Department of Health's Children's Special Health Services division, Ms. Meyer has gained experience in working with a diverse population of children with special health care needs, including infants diagnosed with a genetic disorder or hearing loss identified through newborn screening. Being culturally competent and aware of the struggles of families is a key attribute in the administration of her position.

Jerusha Olthoff, Program Director (PD), has been employed with NDCPD/ND EHDI for 13 years. She has her Master of Science in Management from Minot State University and has served as the PI on the CDC ND EHDI-IS project since 2011. She began as a follow-up coordinator in 2006 and led the training and inclusion of EI providers within the EHDI system. Throughout the past 13 years, she has worked in a variety of capacities within the ND EHDI program from a follow-up coordinator to the ND EHDI program director. Beginning November 2016, Ms. Olthoff took on the role of the HRSA funded ND EHDI program director. This provides a great opportunity to better align both funding agency goals and provide greater efficiencies for the ND EHDI program. Ms. Olthoff's diverse work experience within the ND EHDI system has added to the ability to understand the specific needs for data collection and overall ND EHDI system improvement.

Sue Routledge, Follow-up/Data Coordinator, has been employed with NDCPD/ND EHDI for 14 years. She worked as a Medical Technologist for 18 years prior to joining ND EHDI and has a B.S. in Medical Technology, licensed through the American Society of Clinical Pathologists (ACSP). Ms. Routledge has been a ND EHDI follow-up coordinator since employment and added to her duties in October 2013 as a CDC ND EHDI-IS Data Coordinator. Throughout the past 13 years, she has provided a variety of services to the projects including intensive follow-up of infant populations with incomplete hearing care, trainings to health care providers (hospital staff, primary care physicians, audiologists) and early interventionists as well as the facilitation of many community visits around the state. She is extensively knowledgeable utilizing the online reporting system, OZ eSP, having developed several training manuals to facilitate trainings. She monitors and maintains assurances of complete data collection and has compiled the yearly CDC Hearing Screening and Follow-up Survey (HSFS) since 2005. Additionally, she is knowledgeable in Quality Improvement Strategies and has completed several PDSA initiatives. Ms. Routledge's work experience provides an overall knowledge of ND EHDI's progress/challenges and insight for advancement toward an alignment of EHDI system efforts.

Christine Brigden, Follow-up/Data Coordinator, has been employed with NDCPD for six years and with the State of North Dakota for 19 years. She is a ND Licensed Baccalaureate Social Worker and obtained her bachelor's degree from Minot State University in 1993. Ms. Brigden has been a ND EHDI Follow-up Coordinator since 2017 assuring infants and children birthed in ND are provided complete timely hearing care with access to EI services. She is knowledgeable in utilizing the ND EHDI online web-based data system, OZ eSP and develop partnerships with local community/ national resources and with neighboring state EHDI partners. She facilitates the development of the ND EHDI statewide quarterly newsletter that envelops the community

partners and is responsible for information sharing on multi-media platforms as well as maintaining and improving the existing ND EHDI website. She has coordinated and participated in the ND EHDI advisory committee and with ND Hands & Voices Family Support program to improve coordination of care of services for children who are DHH and their families.

Data Management Plan

Data Collection, Analyzing and Tracking: During the proposed project period, the ND EHDI project will collect, analyze and track demographic data, hearing screening data, diagnostic, EI enrollment and family support enrollment data. ND EHDI data are collected via a web-based platform (OZ eSP). Staff will monitor data input and analyze the data to determine compliance with recommended reporting standards. The ND EHDI staff will ensure the ND EHDI-Information System is maintained, reporting sources are trained on the EHDI system and that complete, timely data are collected on an ongoing basis.

Data Use for Program Development and Service Delivery: All data collected by ND EHDI represents the span of hearing health care, EI and family support efforts. The data collected include a combination of integrated data collection methods and manual data entry. There are currently no identified limitations for data use. The data are stored within the system for an unspecified amount of time; therefore, the ND EHDI program and other approved providers utilizing the OZ eSP system have access to historical data for long term follow-up and coordination of care. The data also assists in the determination of areas in need of quality improvement efforts. As a result of data collection and analysis, the opportunity for improved service delivery results in higher levels of quality care ensuring children who are DHH are identified through newborn, infant and early childhood hearing screening and receive diagnosis and appropriate EI to optimize language, literacy, cognitive, social and emotional development.

Potential Obstacles and addressing obstacles- The *primary obstacle* in implementing the program performance evaluation is **data collection**. The data is a key contributor to support the evaluation of progress in meeting the expected outcomes. ND pediatric audiologists are inconsistent with timely and complete reporting and referral practices. To *overcome the obstacle* of data collection, ND EHDI staff will implement three key strategies to expand upon current education efforts and engage stakeholders within the EHDI system. Strategies include: 1) expanding collaboration and engagement of state EHDI stakeholders to provide education/training and; 2) expand dissemination of progress measures and outcomes to constituents with the primary focus being ND EHDI stakeholders and data contributors via focused report dissemination, issue briefs, social media, etc. 3) focus on ND pediatric audiologists to determine ways to address barriers to timely and complete reporting.

ORGANIZATIONAL INFORMATION

Organization Description

Current Mission and Structure: The ND EHDI program is implemented through the North Dakota Center for Persons with Disabilities (NDCPD) a University Center of Excellence in Developmental Disabilities (UCEDD) at Minot State University (MSU) and is one of 67

UCEDDs across the U.S. and territories. Like other UCEDDs, NDCPD conducts research, provides services, delivers training and disseminates information. The ND EHDI program is designated as a bona fide EHDI state agent by the North Dakota Department of Health (NDDoH) (Attachment 4: NDDoH MOU). The NDCPD will serve as the lead agency for the ND EHDI Program, as designated by the NDDoH.

NDCPD's **mission** is "to provide leadership and innovation that advances the state-of-the-art and empowers people with disabilities to challenge expectations, achieve personal goals and be included in all aspects of community life" (www.NDCPD.org). Through the network of UCEDDs, NDCPD has access to national, state and local resources that can inform project activities and evidence-based services.

NDCPD's specific management structure includes a core executive team consisting of the Executive Director, an Associate Director of Program Development, an Assistant Director of Project Management, Manager of Office Operations and Finance Specialist (Attachment 5: Project Organizational Chart). This core executive team guides the Center's operational activities which are carried out by teams of core coordinators and individual project directors. NDCPD has a consumer advisory council of 15 members who provide guidance to assure the delivery of culturally, linguistically competent and health literate services.

As NDCPD/ND EHDI is located on the campus of MSU, ND EHDI has full access to all university Information Technology services, library, online instructional resources and media facilities including an interactive video conferencing studio for distance meeting collaborations. NDCPD has an experienced website development staff and support resources through its design lab. These resources are used to carry out a variety of activities that help support the project.

Experience working with the state EHDI system: Both the HRSA and CDC funded ND EHDI projects have been carried out through the NDCPD UCEDD for the past 19 years, on the behalf of the NDDoH. The ND EHDI has trained, implemented and provided technical assistance for ND EHDI's web-based data system (OZ eSP). The ND EHDI program staff have become well known to ND EHDI stakeholders and have developed strong working relationships over the past 19 years, for the benefit of the ND EHDI program (Attachment 3: Biographical Sketches of Personnel).

NDCPD has served as lead agency and fiscal agent for the ND EHDI program for the past 19 years. NDCPD has helped carry out collaborative activities to enhance EHDI in ND. NDCPD hosts statewide collaborative conferences for families and professionals. Many of NDCPD projects work directly with EI services and FSOs and holds the contract with the Region 2 Infant Development (Part C) program. These projects create opportunities for the ND EHDI program to gain increased access to and contact with family support groups throughout the state. Continued funding would carry the momentum of our progress and achieve a higher level of hearing health care in North Dakota.

Scope of Current Activities:
Partnerships: Collaboratively, numerous ND EHDI/NDCPD projects involve regular partnership with national, state and local agencies. NDCPD currently has *formalized* subcontracts and

cooperative agreements with many entities that will support the ND EHDI activities. These include: the NDDoH; the North Dakota Department of Public Instruction; the North Dakota Department of Human Services; ND H&V; FVND; University of ND Center for Rural Health; Pathfinder Parent Center of ND; ND Consensus Council; Health and Disability Advocates; and the Vocational Rehabilitation Services. NDCPD partners with several other agencies throughout the state including the ND Head Start Association; ND Chapter of the American Academy of Pediatrics; ND State Council on Developmental Disabilities; ND Chapter of the American Academy of Audiologists; ND Chapter of the American Speech-Language-Hearing Association; Autism Society of North Dakota; and Minot State University (Special Education, Education, Psychology, Nursing, Social Work, Communication Disorders and Criminal Justice Departments).

Family and consumer connections: NDCPD has extensive links to families and individuals with disabilities and special health care needs. We have an active and engaged Consumer Advisory Council (CAC). The CAC has been meeting regularly for 25 years and includes both primary and secondary consumers, members from typically under-represented ethnic and cultural groups and representatives from ND's disability-related state agencies.

Grant operation experience: Each year, NDCPD operates over 40 grant, contract, or fee-for-service projects. NDCPD has developed a center-based system of support for these projects and have the necessary university support systems to conduct our work. NDCPD has a fiscal officer who works in concert with MSU's grants and contracts staff. These personnel assure that funds obtained are spent on reasonable, allowable and allocable expenditures that are in line with funding agency priorities and regulations. All project directors receive ongoing fiscal management training to assure they are up to date in state and federal policy and guidelines. MSU's grants and contracts office maintains the formal university fiscal records and works with NDCPD managing purchases, personnel and federal reimbursement requests. NDCPD has access to all university resources including human resources, payroll, purchasing and motor pool operations.

Existing Available Resources: The NDDoH and the ND Special Health Services (SHS) has designated, in-kind, an EHDI Coordinator (Joyal Meyer) to provide state level guidance to the ND EHDI program. ND EHDI staff have many years of experience and are highly qualified to guide and implement best-practices for ND EHDI. Located on MSU's campus at NDCPD, ND EHDI has access to printing services, technological and educational resources. ND EHDI has direct access to URLEND experiences through NDCPD where ND EHDI is located.

The ND EHDI program will have access to all university online resources that will be necessary to carry out any ND EHDI telehealth/telemedicine activities. These include computing services, media facilities, Internet connections and an Interactive Video Network studio for distance communications. NDCPD also has extensive website development and computer networking support resources through its Information Technology department. NDCPD has the resources and connections that make it an ideal agency to carry out the goals and objectives of ND EHDI.

Supports available at the community, state, regional and/or national levels: The national technical resource center, National Center for Hearing Assessment and Management (NCHAM),

is frequently utilized by ND EHDI for guidance and education on variety of EHDI topics. The FL3 supports the engagement of families within the EHDI system and the ND EHDI program looks to the FL3 as a resource for furthering family engagement within the ND EHDI system. ND EHDI will continue to partner with the NDDoH SHS, ND Vital Records, ND Newborn Screening Program, ND H&V, FVND, the ND Part C program, the NDSD Parent Infant Program and ND birthing hospitals. Letters of support from the NDDoH and ND Part C can be found in Attachment 7. Additional letters of support from ND H&V, FVND, NDSD PIP, Pediatric Audiology Collective (PAC) and URLEND are available upon request. Partnering with these programs provides ND EHDI with the support necessary to continue the work of incorporating QI best practice processes within the EHDI system of care.

How Elements Contribute to Conducting Program Requirements: The HRSA and CDC funded ND EHDI projects have been carried out through the NDCPD UCEDD for the past 19 years, on the behalf of the NDDoH. The ND EHDI program has a solid foundation of supports, as seen in the organizational chart, (Attachment 5: Project Organizational Chart) that provide the ND EHDI program the ability to meet expectations both required and self-initiated. Collaborative efforts with FSOs, the NDDoH SHS and the Newborn Screening Program further expand support efforts beyond ND EHDI's foundational capacity. Through experience, partnerships and internal resources, ND EHDI has provided education, training, continued TA and EHDI system enhancement for the past 19 years. The current staff are well known to ND EHDI stakeholders and have developed strong working relationships for the benefit of the ND EHDI program which support progress within the EHDI system.

Following the Approved Plan and Accountability for Federal Funds- ND EHDI staff and EHDI partners who contribute to goal progress will continue to have regular meetings and utilize the work plan and logic model to assist in the continued adherence to the approved plan. NDCPD will utilize MSU's business office systems and protocols, including the MSU Grants Management staff, to assure fiscal efficiency, allowable and allocable costs and optimal impact. Our financial and personnel management documents are housed with the MSU business office which also has all NDCPD audit reports, fiscal reports and personnel management materials available for inspection by request. Mr. Kevin Kvale is NDCPD's Fiscal Specialist and is responsible for management and coordination of all NDCPD funding. He is the center liaison to MSU's business office and university fiscal services. Mr. Kvale provides fiscal support and coordination of all NDCPD funded projects, including timely information and data support.

How unique needs of target populations of the communities served are routinely assessed and improved- ND EHDI engages in regular monitoring of reporting activities by EHDI health care and intervention providers. The analysis of data system utilization allows ND EHDI to understand if the needs of the target population are being met in a timely and consistent manner. Deficiencies identified by ND EHDI staff are used in conjunction with JCIH recommendations to promote best-practice system changes in ND EHDI processes.

The ND EHDI program has been fortunate to have all birth hospitals in the state fully participating in the EHDI process. The ND EHDI program has well established working relationships with ND's birthing facilities, audiologists, EI programs and FSOs. The relationships have worked well and allowed individually identifiable data to be captured at the

screening, diagnostic and EI phases of EHDI. The HRSA ND EHDI activities will allow for community visits and further education to support consistent communication with EHDI stakeholders.

The ND EHDI program utilizes Vital Records birth numbers as a denominator and basis for comparison of a complete data set. Vital Records provides the ND EHDI program with individually identifiable data on every occurrent birth including demographic and age specific data. ND EHDI will promote and utilize quality improvement methods to address identified areas in need of improvement.

Ability to Facilitate Partnerships and Engage Families, Health Professionals and Service Providers- The ND EHDI program has worked with families, health professionals and service providers to strengthen capacity and improve partnerships in the EHDI system. The ability to engage providers, families and EHDI stakeholders, in general, has been a key attribute to ND EHDI program progress, thus far. Building from the current network of health professionals, service providers and family support organization partnerships, ND EHDI has access to a variety of engagement opportunities. Staff have worked closely with the ND H&V family support organization since its inception in 2010 and sees this relationship as a venue for family engagement opportunities within the ND EHDI program. The expansion of family support services will include collaborating with the Family Voices of ND organization and other family support service providers, as identified.

The ND EHDI staff have well-established lines of communication with all key EHDI stakeholders in ND. Communication is facilitated via Zoom meetings, email communication, one-to-one calls, trainings and regular meetings. ND EHDI will utilize current methods of engagement to expand upon partnerships to ensure the implementation of a comprehensive and coordinated state system for children up to age 3.