UTAH PROJECT NARRATIVE

INTRODUCTION (Criterion 1)

The goal of this initiative is to support the development of state programs and systems of care to ensure that children who are deaf or hard-of-hearing (DHH) are identified through newborn, infant, and/or early childhood hearing screening (ECHS) and receive timely diagnosis and appropriate early intervention (EI) to optimize their language, literacy, cognitive, social and emotional development. Program objectives are to increase the number of newborns and infants who receive timely Early Hearing Detection and Intervention (EHDI) milestone attainment as defined by the Joint Committee on Infant Hearing (JCIH) Position Statements, 2007 and 2019. Specifically these are: to increase by 1% 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 (NBHS) no later than 1 month of age; increase by 10% from baseline, or a minimum rate of 85%, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age; and increase by 15% from baseline, or achieve a minimum rate of 80%, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age. In addition, using data collected from year 1 as baseline data, additional grant goals for years 2-4 are to increase by 20% from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age; increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age; and to increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program.

As Utah EHDI is a formidable program and has the proven ability to work hard, achieve grant project goals, and already has strong stakeholder partnerships, it is with confidence that this application is written. With this funding opportunity, Utah EHDI will: 1) lead efforts to engage all EHDI system stakeholders to improve developmental outcomes of children who are DHH, 2) ensuring that 1-3-6 milestones are met while reducing lost to follow-up/documentation LTF-U/D), 3) identifying ways to expand state capacity to support hearing screening in young children up to three years of age, 4) strengthen capacity to provide family support and engage families with children who are DHH throughout the EHDI system, 5) educate and engage health professionals and service providers on all aspects of the EHDI system, 6) improving coordination of care and services for children who are DHH and access to EI services, 7) 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, 8) develop a plan to address diversity and inclusion in the EHDI system.

NEEDS ASSESSMENT (Criterion 1)

Each year approximately 100 infants are born in Utah and diagnosed as DHH. This number closely aligns with the national congenital DHH incidence rate of 2 in every 1,000 infants. Although these numbers may appear small, hearing loss* (HL) is one of the most frequently occurring birth defects, and the consequences of permanent hearing loss can have long-term detrimental impact on all aspects of a child's development when late-identified.

*Footnote: In this document HL will be used for simplicity, however, it is acknowledged that for an infant *born* with hearing outside the typical range, there is no "loss".

When children who are DHH are identified early, fit with appropriate hearing aids or cochlear implants, have access to language, and receive EI services from trained staff, most are able to progress at age-appropriate rates (Kennedy et al., 2006; Moeller, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998), and require few, if any, special education services. Additionally, there is a cost savings, primarily in reduced need for special education services, of at least $400,000 per child (Grosse, 2004; Mohr et al., 2000). In 1998, the Utah State Legislature passed a law, UCA 26-10-6, requiring all birthing facilities to implement universal NBHS programs by July 1, 1999, including out-of-hospital (OOHB) birthed infants. Now, all 50 states and the District of Columbia have EHDI programs established either by law or through voluntary compliance (ASHA, 2019). This represents the growing awareness across our nation suggesting the understanding of the critical need to identify babies with hearing differences as early as possible, consistent with the federal passage of Public Law 115-71, "Early Hearing Detection and Intervention Act of 2017" which re-authorized EHDI for five additional years.

The national EHDI benchmarks for hearing screening and follow-up are known as the "1-3-6" goals – screening before one month, diagnosis before three months, and EI enrollment before six months. Prior to the implementation of universal screening, the average age at which HL was identified in children was 18 months to 3 years of age (Commission on the Education of the Deaf, 1988). The most recent published figures from the Centers for Disease Control (CDC) EHDI Hearing Screening and Follow-up Survey (HSFS 2016), estimates that for the 49 states and 7 territories reporting, 25.4% of the infants who did not pass screening through an EHDI Program are considered "lost to follow-up" or "lost to documentation" (LTF-U/D); if removing contacted yet unresponsive the national lost to follow-up rate is 18.1%; these infants, already failing initial screening, have a higher risk of HL and greater efforts need to be made to track and document their hearing status. Of those infants who were identified as DHH (subsequent to the initial screening and follow-up) only 67.2% were enrolled in EI Programs.

Utah EHDI has worked hard over the past several years to improve EHDI milestone attainment and is performing better than the national average in all areas. Recognizing the importance of early identification of HL, Utah has been a leader since the early 1970's in developing innovative strategies for early identification of congenital hearing loss. Utah EHDI's Cytomegalovirus (CMV) Public Education and Testing Law (2013) forced the Utah timelines to '½ -3-6' in order to screen and re-screen before 2 weeks in order to complete CMV testing before 21 days of age, if needed. CMV testing has also improved our 3-month milestone attainment.

Virtually all (over 99.1%; 99.6% excluding deceased/refused) of the newborns in Utah are screened for HL. Through great efforts, Utah EHDI has worked to ensure infants are not LTF-U/D. Over the past several years, Utah has seen a significant decrease in LTF-U/D rates; 31.1% in 2013 down to 13.9% in 2014 and 12.9% in 2015. With recent updates to CDC LTF-U/D definitions (removal of contacted but unresponsive), in 2016 we only had 2% LTF-U/D and 3.5% in 2017. For 2017 births, of those referred from the initial screenings (less deaths), we are happy to report that only 2.5% did not complete outpatient (OP) screening (2.7% of those who referred inpatient (IP) screening were recommended to go straight to diagnostics). Of the 2.5% that did not complete an OP screening, 22% of this population refused testing, of which 27.3% (of the 22%) were OOHBs which historically are the infants most likely not to complete the NBHS process (of those who *missed* hearing screening, 76.5% were OOHB, of which 36.3 %

refused testing). For all infants referred for diagnostic testing, results could be documented for 89.4% (less refusals, deaths, and those moving out of jurisdiction) at the end of the calendar year.

It is important to recognize, however, that NBHS is only the first step in a process to identify babies who are DHH and provide them and their families with timely and appropriate services. The benefits of early identification are only fully realized when a child who fails the initial hearing screening completes the necessary follow-up including re-screening, diagnosis, access to communication, and timely referral and enrollment in EI services. Additionally, this follow-up must be linked to the child's medical home for collaboration and reinforcement. Previously, National Performance Measure (NPM) 12 from the Maternal and Child Health Bureau (MCHB) Block Grant (Title V Children and Youth with Special Health Care Needs/CYSHCN) was to monitor and report the "percent of newborns who have been screened for hearing before hospital discharge". As this has been almost fully met nationally, a new set of measures was enacted in 2016; NPM 11 is now the % of children with or without special health care needs having a medical home, which is one of Utah's selected measures. Of utmost importance, for the benefits of universal NBHS to be available to babies and their families, screening must be appropriately coordinated and linked with diagnostic and EI services in a way that is family-centered and culturally competent.

Goals developed for this project are consistent with the Healthy People 2020 Goals that seek to (1) increase the quality and years of a healthy life; and (2) eliminate our country's health disparities. Objective 28-11 is to "increase the proportion of newborns who are screened for HL by age 1 month, have an audiological evaluation by 3 months, and are enrolled in appropriate intervention by age 6 months". Goal 28-13 is to "increase the proportion of persons with hearing impairments who have ever used a hearing aid or assistive listening device or who have cochlear implants." (Although many professionals consider enrollment in appropriate EI to include amplification devices, Goal 28-13 specifically addresses amplification.) Additionally, Goal 16-23 (revised) is written to "increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, and coordinated systems." These NPMs are at the core of the Utah EHDI program. Additionally, given the growing emphasis on understanding life course theory and its implications for maternal and child health, the goals of this project will also incorporate current life course concepts. NBHS programs are in a pivotal position to observe and participate in "factors that influence the capacity of individuals or populations to reach their full potential for health and well-being". The Utah EHDI team fully supports the concept that early experiences and events have a profound effect on an individual's future health and development; specifically, early identification of HL, timely intervention services, and connection to a medical home with appropriate family involvement.

Utah is the thirteenth largest state in the nation and is a largely rural and frontier state. The majority of the population resides along the Wasatch Front (Northern UT), a 75-milestrip running from Ogden to Provo, with Salt Lake City, the state's Capital, in between. The Wasatch Front comprises only 4% of the state's land mass, but 75% of the population. Utah's 2017 population count is estimated at 3,101,833. Utah is known for its signature demographics, which include the youngest population, largest household sizes, and one of the most rapidly growing populations. The population of Utah is primarily white and non-Hispanic with the overall minority share of the population much lower than the national average. In 2017, there were

49,665 live births to Utah residents: 86.2% Caucasian, 1.3% African-American, 2.29% Asian, 1.19% Native Hawaiian or Pacific Islander, 0.91% American Indian or Alaska Native, 1.19% Unknown, and 6.88% Other. Roughly 16% identified as Hispanic with an estimated 84% identifying as Non-Hispanic. Utah has 8 distinct American Indian tribal nations. American Indians were the least likely of all Utah racial/ ethnic groups to have access to needed medical care, with 38.2% reporting that they could not obtain such care, compared to 15.9% of all Utahns. They also have a high poverty rate (28.8% compared to 12.6% statewide) and uninsured rate (21.5% compared to 12.7% statewide) (UDOH: *MOVING FORWARD*, 2010 & 2016).

U.S. Linguistic demographics are rapidly evolving, with approximately one in seven Utah residents older than age five speaking a language other than English at home. 20 of Utah's 29 counties are designated Health Professional Shortage Areas and eleven counties are designated as Medically Underserved Areas. In these areas, access to health care and appropriate medical and audiological follow-up is difficult, at best**.** One in five Utah adults is living with a disability, with the most common being mobility-related disabilities followed by cognitive disabilities. Utahns with disabilities are more likely to be female, Native American/Alaskan Native, and live in Central Utah, Southeast Utah, Tooele County or TriCounty local health districts. Persons with disabilities are also more likely to report lower education and income levels as well as a lack of health insurance when compared to those without disabilities. (Utah's Vital Statistics: Births and Deaths, 2017)

Utah continues to report having the highest birth rate in the U.S. with 15.7 live births per 1,000 total population. Utah is home to 879,000 children; approximately 30% of our state's population. 71,000 or 7% of these children are uninsured, which is higher than the national average. A disproportionate percentage of uninsured children in Utah are Hispanic - the highest in the nation. The uninsured rate for Hispanic infants is directly related to a health disparity as they are twice as likely to be uninsured than non-Hispanic infants and children. Utah's uninsured rate for children increased last year; 1 of only 9 states to do so. Utah has a poverty rate of 11% with the median income being $68,358.00.

Refugees represent an increasing demographic and Utah has received the largest population of refugees arriving in the US since 1988 (45,000). As of 2015, it is estimated that there are 25,000-50,000 refugees, speaking more than 40 languages, living in Utah; the majority of whom live in Salt Lake County. Utah welcomes approximately 1,100 refugees each year. Since 2009, the majority of arrivals have been from six populations: Iraqis, Somalis, Bhutanese, Karen, and Congolese from the Democratic Republic of Congo. Additionally, there have been significant Sudanese, Iranian, Eritrean, Karenni, Burmese, Afghani and Cuban arrivals during the same time period. With this influx of population, the potential for cultural barriers is significantly increased. Barriers to completing the EHDI process for families include language/cultural/health literacy. Data concludes that migration is on the rise and edging nearer to pre-recession levels. In 2017, 46% of population growth was contributed to migration.

Utah's adult lesbian, gay, bisexual or transgender (LGBT) population is 82,460, or roughly 3.7% statewide. Of this population, 26% are raising children. It was noted on KSL News in March 2015 that Salt Lake City, the capital of Utah, has the 7th highest percentage of adults who

identify as LGBT in the nation. It was also noted on KSL news in July 2019 that Utah ranks second highest in the nation for support of LGBT nondiscrimination laws.

Given this data that supports such a large population, it is extremely imperative that resources are allocated to continue to make strides with populations that are potentially predisposed to social and health determinants. Foundational Principles released for Healthy People 2030 states what Utah EHDI already wholeheartedly believes: "investing to achieve the full potential for health and well-being for all provides valuable benefits to society', and "achieving health and well-being requires eliminating health disparities, achieving health equity, and attaining health literacy."

Utah EHDI is housed within the Utah Department of Health's (UDOH) Bureau of Children with Special Healthcare Needs (CSHCN), a program of MCHB. Housed in the same bureau and building is the Baby Watch Early Intervention (BWEI) program, facilitating partnerships to collaborate on aligned activities. Utah EHDI is fortunate to have diverse stakeholders including a well-established and active Newborn Hearing Screening Advisory Committee (NBHSAC), this committee is discussed in further detail in Methodology.

The Utah EHDI Program is outlined in Utah Rule (R398-2-4). In rule, all birthing facilities require audiological oversight as this is an essential role to the success of hospital-level NBHS programs. This aligns with the recently published 2019 JCIH Position Statement, which states "Audiology oversight is recommended for all state/territory hearing screening programs both at the systems level and at the individual program level." Utah has 44 birthing hospitals, 1 children's hospital, 16 free-standing birthing centers, and over 130 midwives birthing across the state. Of the 45 hospitals, 10 hospitals (all urban) have in-house audiology, 32 hospitals have off-site audiological oversight, and 3 currently do not have audiologists as part of their program. Given the lack of pediatric audiologists in Utah (discussed in more detail below), providing audiological oversight for rural and frontier hospitals has proven difficult. The Utah EHDI Audiology Coordinator provides oversight for Utah's OOHB midwives.

Although the number of annual births in Utah is decreasing, OOHBs are increasing. In 2017, there were 1435 infants born out of hospital. Historically, this demographic has been difficult to get infants screened; however, significant effort has been made to ameliorate the barriers. These include providing screening equipment, site visits, midwife-specific trainings, and report cards. Since 2007, Utah EHDI has made screening infants born out of the hospital a top priority. Each year, as budgets allowed, new otoacoustic emissions (OAE) equipment is purchased and placed with willing midwives. Because of this initiative, we were able to screen 92% of OOHB in 2018. This demographic is also difficult to achieve diagnostic follow-up due to a variety of reasons, including lack of insurance access, access to low-cost services, religious beliefs, and general distrust of government and western medicine. Previously, UDOH CSHCN clinics provided low or no cost audiological evaluations as part of a multidisciplinary clinic; however, due to budget cuts, the clinics closed in 2015. This provided a significant challenge for Utah EHDI's follow-up for this demographic. The CSHCN Bureau Director saw this need and allowed Utah EHDI audiologists to provide audiological follow-up, including infant diagnostic auditory brainstem response testing (ABR), free of charge as a public health service on a case-by-case basis.

Timely, accessible, quality infant and pediatric audiology (IPA) services are essential for meeting national EHDI 1-3-6 guidelines. These milestones put forth by the JCIH (2007, 2019) are evidence-based recommendations to maximize linguistic competence and literacy development for children who are DHH. Any barrier to attainment of these milestones directly impacts a child's opportunity to learn language and be on par with their hearing peers in communication, cognition, reading and social-emotional development (JCIH Position Statement, 2007). The following 1-3-6 milestones comparison data is reflected using the most recently published CDC EHDI data (2016 HSFS).

Nationally, 94.8% of babies received a hearing screening before 1 month of age. Utah is doing well at exceeding the national average by screening 98% of infants before 1 month of age, despite significant barriers (e.g. rural/frontier communities, OOHBs). The nation is less successful at diagnosing babies before the 3-month milestone at 75.9%, but again Utah is doing better with 82.5%. The 6-month milestone benchmark is for >90% of infants diagnosed with HL to enroll into EI services. The national attainment of this milestone is still sub-par with only 67.3% of infants enrolled before 6 months; Utah's enrollment rate before 6 months is 81.6%, although 99% of our infants were referred to EI services. The national LTF-U/D rate for 2016 was 25.4%; 18.1% excluding parents contacted but unresponsive. As stated previously, Utah has shown tremendous progress in reducing LTF-U/D; down from 31.1% in 2013 to 2% (unknown + unable to contact) in 2016. These are families that did not pass a hearing screening and didn't follow-up with their rescreen or diagnostic evaluation, or their results were not reported to Utah EHDI. Utah's 2017 LTFU rate was 3.5% (HSFS data submitted but not yet published by the CDC).

There are many reasons a family may be LTF-U/D, in fact, most often families aren't truly "lost", but did not follow-up due to other circumstances. This can be due to parents not wanting to bring their newborn back to a hospital or clinic; a primary care physician (PCP) or nurse may communicate the failed screening was likely due to fluid, devaluing the screening process; parents may be overwhelmed at home; or an infant may have special healthcare needs that may make hearing screening less of a priority. Utah EHDI has a dedicated follow-up (FU) coordinator to contact families who have not yet completed the EHDI process, or when results have not yet been received. This team member works closely with families, hospitals, midwives, audiologists, and medical providers in order to ensure each infant completes the process. She will also provide resources to families when financial barriers are present.

Healthy People 2020 details four components affecting access to quality health care: coverage, services, timeliness and workforce, with the number one barrier to services being lack of availability. The nationwide shortage of pediatric audiologists is well-known, and is certainly true and even more so in Utah, particularly those specializing in infants. Utah EHDI maintains a close partnership and record of audiologists providing pediatric testing. Per our records, we have 24 audiologists with experience in infant/pediatric ABRs, most of which are along the Wasatch Front or Southwestern Utah. For families living outside these areas, it's a 2-3 hour drive or more. Even for those living in the Wasatch Front there can be a 6-week wait time for a diagnostic ABR appointment, as 75% of diagnostic ABRs are done at the children's hospital in the Salt Lake Valley. Another challenge has been a high turnover rate at the children's hospital, making it difficult for families to have continuity of care for follow-up and fitting appointments. Utah

EHDI has continued to provide tele-audiology (TA) services consisting of ABR (frequency-specific, click, bone-conduction) and DPOAEs in order to reduce the number of infants LTF-U/D due to lack of access.

In Utah, not only do we strive to meet the JCIH 1-3-6 milestones, there is also a significant number of providers practicing due diligence to promptly and timely diagnose congenital Cytomegalovirus (cCMV). Possible sequelae of a maternal CMV infection during pregnancy include hearing and vision loss, developmental delay, brain damage with or without microcephaly, seizures, cerebral palsy, and cognitive impairment. CMV is the most commonly occurring congenital infection in developed countries, with more than 40,000 women in the US contracting the CMV infection during pregnancy each year. In Utah, this is almost one baby born with congenital cCMV every day. While there are usually no harmful effects when a healthy person or child is infected by CMV, it can cause damage to an unborn infant if the mother is infected with CMV during pregnancy (Kenneson & Cannon, 2007). Of particular concern for EHDI is that cCMV is the leading non-genetic cause of childhood sensorineural hearing loss (SNHL) which is often progressive in nature (Grosse et al). Longitudinal data has estimated that 1 in 3 children in Utah with SNHL have lost their hearing secondary to a cCMV infection. Congenital CMV can often go undetected at birth because most newborns are asymptomatic with no obvious symptoms except for a possible failed hearing screen. Of note is the fact that more than 50% of cCMV children who go on to develop HL, will have typical hearing at birth (which also supports the case of Early Childhood Hearing Screening).

In March 2013, Utah became the first state in the nation to pass CMV legislation. In July of 2013 the Cytomegalovirus Public Education and Testing Law (H.B. 81, 2013 General Session, UCA 26-10-10) went into effect. This two-pronged mandate charges UDOH with the creation of a public education program to inform pregnant women and women who may become pregnant about the occurrence and transmission of CMV, the birth defects that cCMV can cause, methods of diagnosis and available preventive measures. Secondly, the law directs medical practitioners to test infants for cCMV who fail the NBHS and inform the parents about the possible birth defects that cCMV can cause.

Six years after the CMV mandate began, 109 babies have been identified with cCMV. This is statistically significant, as without the mandate these babies may not have been identified with cCMV. This identification allows for close surveillance of hearing which is imperative since cCMV induced SNHL is often progressive in nature. Another important advantage of identifying these cCMV babies early is that it allows for education and empowerment of parents early on in the care for their children who may have special needs. For example, BWEI has listed CMV as a qualifying diagnosis for enrollment in EI services allowing for monitoring and/or providing services for the child's global development. For cCMV babies that have gone on to have typical hearing at diagnostics but are still at high risk to develop HL, the opportunity to be involved in EI is a valuable resource for parents to learn more about early hearing and language milestones.

Hearing targeted cCMV screening also enhanced Utah's ability to meet EHDI's important goal of diagnostics before 3 months. Data for 2 years prior to the mandate (2011 to 2013) indicated that only 59.5% of all babies needing diagnostics had them completed by 90 days compared to 75% in the first 18 months after the mandate. When comparing only babies that had evaluations

completed by 90 days, the percent increased from 75% prior to the mandate to 82% after the mandate. In addition, the mean # of days for diagnostics to be completed for those who met the 90-day goal, decreased from 39 days before, to 33 days after, the mandate. This data supports the notion that the cCMV hearing targeted approach interfaces well with existing NBHS programs and actually improves attainment of important EHDI goals. In collaboration with researchers at the University of Utah, Utah EHDI published early data from our CMV testing mandate, Outcomes from a Hearing-Targeted Cytomegalovirus Screening Program. *Pediatrics,* 2017 Feb;139(2). The importance of timely cCMV testing is underscored in the new JCIH 2019 Position Statement (just released) where testing for cCMV infection is listed as an "additional testing consideration".

Early Intervention (EI) services are provided through a family coaching model that focuses on helping children meet goals in all areas of development. All services take place in the child's natural environment (home, child care, etc.) and are tailored to meet the individual needs of the child and family. The purpose of the Utah Baby Watch Early Intervention Program (Part C) is to enhance early growth and development in infants and toddlers who have developmental delays or disabilities or both, by providing individualized support and services to the child and their family. EI services are customized for every child and family, and are provided by a team of qualified personnel that may include: service coordinators, child development specialists, speech-language pathologists, registered nurses, occupational therapists, physical therapists, dieticians, social workers and/or behavior specialists.

Although there is almost universal support for the concept of early identification of HL throughout Utah, many barriers to timely diagnosis, referral and enrollment into EI still remain. Specifically, infants who do not receive appropriate follow-up after failing the initial NBHS screen, infants who don't receive a timely diagnosis after failing a second screen, and infants diagnosed as DHH not receiving timely and appropriate EI services (including the connection to a medical home), highlight weaknesses in the current system.

For 2017 data reported to the CDC, out of 98 children diagnosed with HL, 96 (98%) were referred to EI (the two infants not referred were initially diagnosed as permanent, but later "resolved"). Seventy-nine of those referred to EI were referred prior to 6 months of age (82.3%). This is an improvement of 3.2% since 2013. Of those children diagnosed with HL, 74 were enrolled (75.5%) in EI. Of the 74 who were enrolled, 56 were prior to 6 months of age (75.7%). This is an improvement of 2.4% since 2013. Of the 24 children that were not enrolled in EI, 3 (4.1%) were LTFU for EI services. All other children were categorized as monitoring only (3), family contacted unresponsive (4), moved out of jurisdiction (4), infant died (3), or parents/family declined (7). A few needs are present here and will be investigated with this new grant project; researching why families are declining or unresponsive to contact, and/or why they choose "monitoring only". The latter is particularly important as we have recently discovered that the "monitoring" of those families doesn't seem to be happening by the EI program(s).

For families of newly diagnosed children who are DHH, there is only so much support they can receive from a pediatrician, early interventionist, etc. Parents often find themselves meeting a DHH person for the first time, and it happens to be their own child. Speaking with other parents who have experienced the diagnostic process and lifelong odyssey after diagnosis - the feelings

of fear upon initial diagnosis, worries about the future, the joys of success, etc. are areas that cannot be fully understood by professionals despite their expertise (Quittner et al, 2010). Parent-to-Parent (P2P) support can fill in gaps in the EHDI system that professionals cannot.

In the 2018 Family Leadership in Language and Learning Center (FL3) Needs Assessment, it states "families need to be offered comprehensive information about services and support at different points in their child's life; coordinated, trusted resources; contact with and support from other parents who share their lived experience; increased support for underserved families; and access to DHH role models". It is a connection in which parents can have emotional and informational support they may not receive from other resources.

As P2P support and family engagement are so important to the achievement of this funding project's goals, it should be noted that Utah families of DHH children have received P2P support specific to DHH needs during the past three years thanks in large part to the current HRSA Universal Newborn Hearing Screening grant funding and partnership with our chosen Family-Based Organization (FBO), the Utah Parent Center/Utah Family Voices (UPC/UFV). Since Utah hasn't had a Hands & Voices (H&V) chapter in many years and efforts to revive the chapter were not successful, the decision was made to collaborate with a program that Utah EHDI already has a solid relationship with, the UPC/UFV. A Memorandum of Understanding (MOU) was created in coordination with the UPC/UFV to hire a parent of a child who is DHH to be the EHDI Parent Consultant (PC). This partnership has been crucial in the success of the P2P support aspect of the EHDI Program as the PC contacts every family in the state after their child receives a diagnosis of a permanent HL. Utah EHDI documents the number of families involved in Utah EHDI/UPC family-to-family (F2F) supports, whether the families have been called by PC upon diagnosis, when trying to facilitate follow-up, or when participating in the many EHDI/UPC sponsored family events. The PC facilitates connections with parents with similar diagnoses or geographical location when possible.

The Utah Schools for the Deaf and Blind (USDB) support families by providing deaf mentorship to families enrolled in the Parent Infant Program (PIP) for a period of 3 years (services must begin before the child turns 3). USDB PIP is the contracted EI specialized service provider for children that are DHH. Upon enrollment into PIP, the families are informed about Deaf Mentor services from their Parent Advisor and the language orientation team (one Listening and Spoken Language (LSL) deaf adult and one American Sign Language (ASL)/English Deaf adult) who discuss all of the communication approaches available. If the family decides they would like to learn ASL and Deaf culture, they qualify to participate in the Deaf Mentor Program. One barrier to Deaf Mentorship for all families in Utah is that families must be enrolled with USDB PIP. Families who choose not to enroll in PIP services are not eligible to receive a Deaf Mentor. Also, as mentioned previously, families must choose ASL for communication to qualify for Deaf Mentor services through PIP. Utah EHDI has begun efforts to investigate the possibility of filling the gap for these services to families who are not participating in PIP or not interested in learning ASL/Deaf culture, including learning more about what is available through the Ski-Hi program.

While infants who are identified as cCMV+ continue to receive audiological follow-up, and are tracked by Utah EHDI due to their risk factor, the main focus of Utah EHDI has always been birth to 3, ensuring that all infants are screened, diagnosed, and referred to EI in a timely manner.

However, “research indicates that by the time children enter school, at least 6 in 1000 are deaf or hard of hearing.” (ECHO, August 2019). When a child is diagnosed with progressive or late-onset HL, the PC currently contacts the family and aids in providing resources, however there has not been an emphasis on these late diagnoses other than documenting them and making sure the family gets connected with appropriate resources (including receiving the Utah EHDI Parent Notebook). The Reauthorization of the EHDI Act of 2017 includes an expanded focus on identifying children who are DHH up to 3 years of age. This lends an opportunity for EHDI to collaborate with the Early Childhood Hearing Outreach (ECHO) Initiative. “The ECHO Initiative, housed by NCHAM, serves as the National Technical Assistance Resource Center (NTRC) to assist Early Head Start, Head Start and other early care and education providers in developing evidence-based hearing screening and follow-up practices for children under five years of age” (ECHO, August 2019).

METHODOLOGY (Criterion 2)

Lead efforts to engage all stakeholders in the Utah EHDI system to improve developmental outcomes for children who are DHH

Utah EHDI has a well-established and active NBHSAC which meets quarterly. This committee has several members as defined in statute and is currently composed of five pediatric audiologists from multiple state sites including community health centers, hospitals and schools; a private health insurance representative; a Medicaid and private practice pediatrician representative; a Family Practice physician (currently replacing); a neonatologist (currently replacing); an EI specialist; an Otolaryngologist (ENT); a home birthing nurse midwife; a public health nurse; a Utah Hospital Association liaison; a representative from USDB PIP; two representatives from NCHAM; the Medical Director of the EHDI program; the EHDI Champion from the Utah Chapter of the American Academy of Pediatrics (AAP) (currently replacing); a representative from the Office of Home Visiting (OHV); the Program Manager of the EHDI programs who is also one of the Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) Audiology Faculty; four parents of a DHH child/ren; and the EHDI Audiology, FU, Data and Hearing Aid Coordinators. These meetings are open, recorded and available to the public. New representatives added to the committee in the previous grant cycle include: the MCHB Integrated Services Program (ISP), Early Head Start (EHS), the Division of Services for the Deaf and Hard of Hearing (DSDHH), the Women, Infant’s & Children Program (WIC), DHH Individuals, and the EHDI PC (representing EHDI and the Utah Family-to-Family Health Information Center). A representative from the Office of Health Disparities is available upon request and has consulted with Utah EHDI on specific projects. The by-laws were also updated so a parent sits as the co-chair specifically to promote leadership skills of family members of a child who is DHH and to lead the NBHSAC in creating collaborations between members of family organizations that support infants and children who are DHH. More than 25% of members are parents of children who are DHH or DHH individuals (we have 5 DHH adults on the committee). These members help educate our committee on how to develop culturally competent practices pertaining to the DHH, and what obstacles they face as a family. Family-centered awareness, education and care will be incorporated in many ways with this grant.

As part of each of these meetings we have a formal 20-30 minute education period. Education includes topics such as the JCIH 1-3-6 timeline and how to engage with community

stakeholders; P2P support and family engagement; Etiquette and best practice for communicating with DHH individuals; EI and the PIP collaboration efforts; Improving EHDI Systems Infrastructure; Stakeholder collaboration efforts: OHV, Care Coordination, etc.; Education regarding state protocols, laws and programs; and availability and utilization of DHH mentors.

As outlined in the Evaluation Section, this committee will share the responsibility to monitor the progress of this project. Using partnerships to implement the project strategies at every level provides an opportunity to embed the EHDI concept/philosophy into the infrastructure of numerous public and private agencies. The more stakeholders are involved in each aspect of the "project", the greater the sense of ownership of the EHDI system statewide. With increased ownership comes a greater commitment to sustainability and a wider base of support.

UDOH is one of only a few sites, possibly the only, around the country offering infant diagnostic ABRs utilizing telehealth technology. In the US, there are about 200 telehealth networks with 3500 service sites (American Telemedicine Association/ATA, 2016) and 76% (American Hospital Association, 2019) of all hospitals are now using some form of telemedicine. In Utah, tele-audiology (TA) allows more families, especially from remote areas, increased access to diagnostic evaluations from audiologists who are comfortable testing infants and young toddlers. A survey of US states and territories revealed that nearly half of the NBHS programs reported that the major obstacle to obtaining diagnostic evaluations was due to a shortage of pediatric audiologists (Hayes, 2012). TA allows for increased diagnostic evaluations, audiological management and intervention, and access to EI in order to develop crucial language and communication skills. This in turn allows NBHS programs to reach the 1-3-6 goals of screening, diagnostics, and intervention, especially in areas where infants LTF-U has traditionally been high.

Since 2014, we have been working with Uintah Basin Healthcare (Eastern Utah) to provide diagnostic services for families whose infants have failed their NBHS. Previously, families would have been referred to an urban hospital requiring a 5+ hour round trip plus the additional time spent at the diagnostic site. In 2018, we partnered with Blue Mountain Hospital (in the Four Corners region), a critical access hospital (CAH), which provides services for a significant amount of the Navajo Reservation and is the home base for Utah Navajo Health Services (UNHS) clinics. Without TA, this would require 10 hours round trip, plus testing time. In the last two years, we have also trained two more CAHs to refer to the above TA sites for diagnostic ABR evaluations. For the last 2 years of TA data, Uintah Basin had a 5% (35/37 infants) lost to diagnostic evaluation rate. Of the infants tested at UBH, 3 were diagnosed as DHH secondary to cCMV. At Blue Mountain there was a 28% lost to diagnostic rate, and while this is not ideal, it is a significant improvement from 4 years ago when it was 95% (12/13 infants). We will continue working with the hospitals and clinics to improve follow-up.

Describe strategies for engaging, educating, and training health professionals and service providers in the EHDI system about the activities described

Provider and stakeholder education are critical to the success of National and Utah EHDI programs. Educational efforts should not begin and end at the hospital level. The NBHS process should be discussed throughout all levels of care. It should be introduced prenatally and

postnatally (i.e., prenatal brochures, prenatal education classes, WIC and OHV programs) with conversations occurring when the baby is IP, being discharged, at follow-up appointments with PCPs, ENT appointments, as well as at EI programs if the child is enrolled. These opportunities should not be taken lightly at any stage of the process.

Utah EHDI will use this funding opportunity to broaden its reach through a multi-pronged approach utilizing a variety of educational and training opportunities such as hospital grand rounds, webinars, state conferences, etc. In the previous grant cycle Utah EHDI made inroads with 4 pediatric practices by conducting Learning Communities including the completion of baseline EHDI knowledge surveys to determine the needs and gaps of PCPs. Other stakeholder and professional engagement opportunities that Utah EHDI currently participates and collaborates with, and will continue to do so in this new grant project, include the following groups along with a description of their purpose:

- The Pediatric Audiology Working Group (PAWG) consists of pediatric audiologists from major diagnosing hospitals and private practices, and the EHDI team. This group works on any pediatric audiology/EHDI related current topics or issues.
- PIP and Sound Beginnings (an LSL focused non-Part C EI provider) are both EI programs that provide services in the home and center-based services for infants from birth to 3 years of age that are DHH and their families. Services include group-based activities, educational services, mentoring services, and communication development. Some services are also provided via tele-intervention.
- The Children's Hearing Aid Program (CHAP) Advisory Committee is a Utah EHDI sub-program that consists of an ENT, DHH educator, Speech-Language Pathologist, pediatric audiologist, and parent representative. The CHAP committee ensures that eligible Utah children have access to hearing aid funding and resources so that applicable children are enrolled in Part-C EI services, and that appropriate follow-up services are being met. This program helps remove financial barriers from achieving the JCIH 2007 and 2019 goal that, "the child and family should have immediate access, through their audiologist, to high-quality, well-fitted, and optimized hearing aid technology.
- The Utah Regional Leadership of Education in Neurodevelopmental Disabilities (URLEND) is a group that focuses on training professionals from varying background specialties to move beyond their normal boundaries in order to provide optimal care.
- Two of the Utah EHDI team serve on EHS advisory committees to advise on the importance of hearing screening beyond the newborn stage to detect late-onset hearing loss.

In this grant project, Utah EHDI plans to present or collaborate with even more stakeholders: Utah Speech and Hearing Association, Utah Midwife Organization, AAP, ENTs, obstetricians, Utah Women and Newborn Quality Collaborative (UWNQC). In the past, Utah EHDI has presented at the BWEI Grantee Meeting (statewide EI Program Directors), rural hospital nurses and physicians, USDB Deaf Mentors, Fostering Healthy Children (FHC) (foster care coordinators) and the Children's Hospital. Educational opportunities like these will be continued in this grant cycle. EI providers will be a main target for education and trainings as gaps are evident in the eligibility and referral process from EI to PIP. In collaboration with the NTRC, we will focus educational efforts for stakeholders on ECHS and the 2019 JCIH recommendations.

Utah EHDI has led or participated in quality improvement initiatives for many years. In fact, Utah was part of the National Initiative for Healthcare Quality (NICHQ) improving loss to follow-up project for three years and collaborates closely with NCHAM in assisting in our continued implementation of Quality Improvement (QI). We have an assigned NCHAM QI Advisor who helps us conduct ongoing QI needs assessments and evaluations. NCHAM also provides ongoing technical assistance and support in implementing the chosen QI strategies. Utah EHDI also participated in NCHAM's Tele-Audiology learning community and actively participates in current Utah Department of Health Continuous Quality Improvement (CQI) initiatives. In the last two years, the entire UDOH has been focused on Continuous Quality Improvement Activities (CQI). In coordination with the Department CQI, we have created a HRSA Grant Dashboard to easily update and monitor our grant activities. Within the dashboard, each HRSA grant activity is assigned two staff members to monitor and update the activity. We can also enter a status (i.e., complete, in progress); how often each activity should be worked on (i.e., weekly, quarterly, etc.); the Start and End Date; and Additional Support Needed. This document is monitored and updated by our team, CQI manager, and Bureau Director. For this grant cycle Utah EHDI will focus on CQI in two specific areas: Expansion of screening up to age 3 and LTF-U/D, particularly in the OOHB population.

For 2017 births, Utah reported that 99.2% were screened. Of those not screened: 57.4% died, 2.5% moved, 18.6% declined, 18.6% were homebirths, and 2% transferred with no results. The biggest way to improve the # of infants screened is to increase the OOHB screenings /reporting. When just looking at OOHB (home and birth centers), 90.8% were screened for 2017. As mentioned in the Needs Assessment, the OOHB population is in general a more at-risk population for not completing the EHDI process. In addition, the FU Coordinator spends a significant amount of time finding results LTD. Midwives have been frustrated with the duplication of work, reporting the same demographic data to both VR and EHDI. In an effort to ease reporting for midwives, Utah EHDI has collaborated with VR to update the birth certificate application form that is required to be submitted for every baby. This form will now have a place to enter hearing screening information: date screened and ear specific result (pass, refer, not screened, refused) for both the inpatient and outpatient screenings. The hope is that this will decrease the burden on midwives of reporting results to the state and decrease the % lost to documentation. This version of the VR system has not gone "live", but will in 2020. This grant period will involve education on utilizing it, accountability, as well as efforts to then transfer the data to the EHDI system. The QI activities will include monitoring data quality, who is documenting "not screened" instead of entering data, training on the importance of EHDI and why reporting matters for their patients, and communication methods for working with Midwives. QI activities will also involve Utah EHDI extracting and importing data; however, those activities will be determined after the reporting update goes into production.

Utah EHDI will also be incorporating QI strategies when developing the ECHS program guidelines. During this grant project period Utah EHDI will obtain a baseline of ECHS programs. We will evaluate screening protocols, training methodology, equipment utilized, referrals made, resources available, etc. After the baseline of what is currently implemented across our state is determined, the first QI initiative will be to develop a best-practice periodic hearing screening protocol for EHS and EI programs, and provide training regarding the updated

protocols. We will also review ECHO and other screener training modules to determine how to efficiently and effectively train screeners.

The Utah EHDI Program already has an excellent website; receiving the 2019 annual "Best of EHDI Website" award based on: "Accurate, useful, timely, and comprehensive information that contributes to the accomplishment of 1-3-6 milestones for infants and young children who are DHH; information for various EHDI stakeholders (families, healthcare providers, and interventionist) as well as correct info about the EHDI process; and appropriate and visually appealing design and layout that allows for ease of finding information." The website contains information for families, physicians, hospitals, midwives, and audiologists. Activities include maintaining current links and evidence-based information. Planned updates to the website include more F2F support information, linkage to the ECHO initiative, deaf mentor information, the new Parent Notebook and more resources for family engagement. Informational videos are planned to be created and added to the website, showcasing families of DHH children as well as successful Deaf adult stories. We currently have Facebook pages for "Utah EHDI Family Support and Information" and "Utah CMV - CMV Public Health Initiative". Plans for this grant cycle include creating an Instagram account in an effort to reach more parents on more social media outlets. In order to better serve our Hispanic families, we will explore translating content, not just our current Spanish attachment, on our website.

Describe strategies to strengthen the capacity to provide family support and engage families with children who are DHH as well as adults who are DHH t/o the EHDI system.
With this funding opportunity, Utah EHDI will enhance family support and engagement by continuing our partnership with the UPC/UFV. UPC is the only statewide parent-run organization with programs serving parents who have children of all ages with a wide variety of disabilities and special needs through a research-based P2P model. They provide unbiased information, training, resources, and connections through peer support to families whose children, youth or young adults experience the full range of disabilities including deafness and hearing loss. UFV is an essential part of the UPC work with families of children with special health care needs and the many systems that provide services and respond to their unique needs. The quality work of UFV in this highly specialized area is unparalleled. Their involvement and knowledge of the complex issues to be addressed makes them uniquely qualified for the responsibilities of this grant project. 25% of the project budget has been allocated to UPC/UFV. During the last grant cycle the UPC PC significantly helped to broaden our reach with new stakeholders, as well as meeting families where they are through personal phone calls, community activities, increasing our social media presence, and working with healthcare providers to understand the family perspective. Utah EHDI and UPC plan to further strengthen our EHDI systems by developing more opportunities with community-based DHH mentorship, provider education and training, expanding our partnership with the Utah Division of Services for the Deaf and Hard of Hearing (DSDHH), and collaboration with EI programs. We plan to work with DSDHH to investigate how to provide support to children who have less than a bilateral, severe-profound hearing loss, along with families who may have a child who is Deaf Plus (multiple diagnoses), different cultural backgrounds, and those who may be a refugee, or other underserved populations.

In collaboration with our FBO (the UPC), and the FL3, the PC will be developing and maintaining family engagement and support activities in this new grant project consisting of, but not limited to: Facebook Live "webinEARs", creating an Instagram account to broaden our reach to families, creating a new live resource focusing on families in Utah who are raising a child who is DHH as a way to highlight what "a day in the life" looks like for different families, partnering with the DSDHH Program to investigate further ways to connect families to Deaf adults, research the possibility of holding Family Weekend Retreats at different Universities in our State, investigate the possibility of collaborating with local museums and nature centers throughout Utah to offer DHH Family Nights, and continue to hold Summer Park Play Dates.

Utah EHDI will continue to help achieve success in ensuring that DHH children are identified through newborn and infant hearing screening and diagnosis, and receive appropriate intervention that optimize their language, literacy, and social-emotional development. These efforts will include connecting families to family-to-family (F2F) support services and deaf adult-to family (deaf mentor) services, and improving both the 3 and 6-month EHDI milestones.

Utah EHDI is striving to partner and interact more with EI/PIP to enhance language acquisition for DHH children incorporating the aforementioned principles of early identification of HL with rapid transition into intervention that can provide a rich language environment for the child whose brain is in a critical time period for acquiring language. This includes both educating and empowering parents to help their children in addition to fostering peer parental programs. Utah's strategies include the following:

1. Continued efforts to meet the EHDI 1-3-6 guidelines so that identification of HL is completed in a timely manner with immediate transition into amplification and intervention. As discussed previously, the hearing-targeted CMV screening program has decreased the time to diagnostics. Our research shows that continuing to support our NBHS programs to get CMV testing done by 21 days of life will continue to decrease the time to diagnostics.
2. Provide parents of newly identified children with an information binder regarding hearing loss, options for modalities, interventions and parent and community support, called "the Utah EHDI Parent Notebook". An additional informational supplement will be included for children with a diagnosis of cCMV. We strive for all information to be culturally sensitive and when possible provided in Spanish also.
3. Provide parents with an unbiased and approved review of modality options for their child including a visual-manual approach such as ASL or an auditory-verbal such as Listening and Spoken Language approach via current, evidence-based vetted materials in the above-mentioned Utah EHDI Parent Notebook and through the EHDI PC(s).
4. Enrollment in EI by 6 months of age. We are fortunate in Utah to have excellent EI programs. Incorporated in their program are parent support groups and family activities. Another program, Sound Beginnings is available in northern Utah through Utah State University. We have worked on creating stronger partnerships and greater collaboration with BWEI, USDB PIP, and Sound Beginnings and will continue to do so, particularly in sharing data on those families receiving parent support and deaf mentorship through their agencies, including when parents decline.
5. Provide families access to CHAP which was created to help families in need receive early access to hearing aids for their children.

6. Provide families immediate access to the ISP to assist them with coordinated care planning, education and resources in order for them to make informed decisions. This may include primary and special health care, behavioral health, developmental and educational programs, financial support resources and social services that meet their special needs from infancy through the transition to adulthood, with a strong emphasis on medical home engagement.
7. Upon diagnosis of hearing loss (or at any time in the EHDI process in which a parent needs support and/or resources) community stakeholders should refer parents to the EHDI PC. The PC will reach out to all families of newly diagnosed infants who are DHH in order to provide P2P support. The PC will speak to families about the importance of EI, ways to connect to other families like theirs, upcoming activities for families, etc.

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

During the first 2 years of this grant project, Utah EHDI will create a state plan to expand infrastructure, including data collection and reporting, for hearing screening for children up to age 3 years, in alignment with the EHDI Reauthorization Act of 2017 that highlighted the importance of early childhood hearing screening. The EHDI Team will work with state programs and partners to identify who provides early hearing screening to their young clients, what protocols they are using, emphasize the importance of ongoing screening beyond the newborn period into early childhood, and assisting with training and referral needs. The EHDI team will identify new partners, such as multiple EHS agencies, and increase partnership with current ones, such as OHV and work towards developing a state plan to expand hearing screening for children birth up to 3 years of age to identify late-onset HL. The EHDI team will work with other state stakeholders to utilize current training available to providers. Utah EHDI will also work with the EHDI NTRC in utilizing their results/report from their 1-year environmental scan of evidence-based and evidence-informed approaches to ECHS up to the age of 3 that will hopefully be completed through HRSA-20-048. The results of this scan detailing where screening could occur, mechanisms for collaboration and referral across early childhood programs, and the role of state EHDI programs, could be very helpful to the creation of Utah's plan.

As stated on the AAP National Center for Medical Home Implementation website, a Medical Home is not a building or a place; it is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families; care within a medical home should be accessible, continuous, comprehensive, patient- and family-centered, coordinated, compassionate, and culturally effective. As healthcare providers become more widespread and branch out into more specialized fields, the quality of patient care can begin to diminish due to specific symptoms being treated rather than the holistic care of the patient. This is especially true for infants who are D/HH and a medical home is critical for these children in ensuring that all needs are met so full developmental potential of the child can be reached.

In theory, medical homes are an excellent tool for patients and families; however, achieving a true medical home can be difficult. Listed below are a few ways that Utah EHDI is planning to combat the sparsity of medical homes available in Utah:

- Collaboration with individual providers, committees, and learning communities on the importance of a medical home for children who are DHH, and the importance of comprehensive, culturally appropriate care coordination.
- Collaboration with the Integrated Services Program (ISP) in the Maternal and Child Health Bureau in order to assist children with special needs, including children who are D/HH, receive direct coordinated care and to improve family engagement and involvement. The ISP provides referral and follow-up for EI and other supportive services, facilitates access and eliminates barriers in order for children to receive timely services, makes connections to peer to peer and family support groups, and facilitates the creation of care plans utilizing family involvement that include goals, responsible parties, and activities. Utah EHDI works closely with ISP to ensure that children who are D/HH that are being tracked by EHDI are receiving the follow-up and support services the child and family may need.
- The Medical Home Portal is an organizational website that was created to assist providers and families in working together, to help children with special health care needs to receive quality care, and to improve overall outcomes. The Medical Home Portal currently connects Utah, Montana, Idaho, and New Mexico and provides information, resources, and service directory. Utah children who are D/HH can find information on Utah EHDI, local pediatric audiologists, early intervention services, links to hearing aid resources, and information on additional testing or services due to other symptoms or developmental concerns that are linked with hearing loss. Links are consistently updated, and new information is properly presented, including information on EI services, family involvement, education, medical care, co-morbidity, global development, and language development. The Utah EHDI team has helped author content in regards to DHH subjects. The PC was able to have a pediatrician, Dr. Chuck Norlin, who is the director of the Utah Pediatric Partnership to Improve Healthcare Quality, as well as the Utah Medical Home Portal, discuss the importance of a medical home for children who are DHH on a webinEAR in 2019.
- Education at the level of the medical home is also an important goal. Utah's AAP has an organization called the Utah Children's Care Coordination Network (UCCCN). The meetings are monthly and attendees include 20-30 office managers and care coordinators, the ISP staff, and representatives from UPC/UFV, including our EHDI PC. This is a well-attended, growing and amazing platform to share information and resources. Utah EHDI will continue to participate, including providing training on EHDI.

The medical home model essentially allows for children and their families to have access and support from the healthcare system to assist the child in reaching their full potential. Utah EHDI is currently involved in creating interconnections, collaborations, and updating links to make the medical home model more accessible in Utah, and will utilize the resources available through the NTRC-Patient and Family-Centered Medical Home.

Utah EHDI and the CSHCN Bureau have closely collaborated with Utah Regional LEND (URLEND) program over the past 19 years and will continue our relationship in this next grant cycle. The current Utah EHDI Director has served as URLEND Audiology Faculty since 2011 and as the IPA Program Coordinator from 2012-2018. One of URLEND's purposes is to engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations; the need for hearing screening up to age 3 years, the benefits of a family-

centered medical home and the importance of communicating accurate, comprehensive, up to date, evidence-based information to families to facilitate the decision-making process. The URLEND program participates in these goals by training the next generation of leaders of healthcare professionals and families with children and youth with special health care needs. Specific training for infant and pediatric audiologists is offered through the URLEND grant supplemental funding set aside for future leaders of pediatric audiology and the EHDI program is heavily emphasized in this URLEND training.

The URLEND curriculum, which is a 9-month program for 30-35 masters and doctoral level healthcare providers, emphasizes the importance of follow-up screening, care coordination, and enrollment in EI services that may be necessary to an infant who is DHH. Many URLEND trainee leadership projects over the years have involved improving systems of care for infants who are DHH. The URLEND faculty will work directly with the staff and faculty of Utah EHDI to coordinate and collaborate on activities supporting the EHDI project goals. In collaboration with URLEND we provide ECHS services and FU at the South Main Clinic. This community health center provides primary care services for foster children, teen mothers, refugees, and other high-risk populations. Hearing services are provided by URLEND IPA trainees at no cost to families. Several URLEND faculty members participate in the NBHSAC.

Propose plans for participating in the Annual EHDI Meeting (Criterion 6)

In the budget narrative (see Attachment), one will see that two staff members and one family leader are budgeted to attend the Annual EHDI Meeting. This conference is one of the premier mechanisms that provides professional collaboration and technical assistance to state grantees. These trainings and networking opportunities are essential for learning from and sharing successes with other states, as well as garnering ideas from national and international experts on how to improve our program. We take the opportunity to meet with our HRSA Project Officer in person at each conference. Utah EHDI is very active in presenting at the National EHDI Conferences and always has a strong presence. At least one abstract is submitted by Utah EHDI every year.

Provide a statement re: project sustainability (Criterion 4)

Using partnerships to implement the project strategies at every level provides an opportunity to embed the EHDI concept / philosophy into the infrastructure of numerous public and private agencies. The more stakeholders are involved in each aspect of the "project", the greater the sense of ownership of the EHDI system statewide. With increased ownership comes a greater commitment to sustainability and a wider base of support. Utah EHDI will continue to broaden this base of support by strengthening current partnerships and creating new ones. Additional funding sources are continually sought and some that may be able to be utilized through legislative and executive office support in the future could be dispersion of Title V funding towards Utah EHDI and/or increasing the "heel stick kit" fee to help fund our program (currently a small % of these kit fees - the cost for the blood spot collection cards for mandatory newborn screening - are allocated to help fund EHDI). The EHDI program already has strong executive support, particularly the CSCHN bureau director who has committed her assistance in sustaining Utah EHDI.

DIVERSITY

Utah EHDI will work with the Office of Health Disparities (OHD) to identify targeted areas of

improvement at all stages of the EHDI Process. In previous discussion with the OHD it was noted that VR collects granular data on the birth certificate that may be useful to disaggregate ethnicity such as Asian and Pacific Islanders. Through this disaggregation, they have identified many birth outcome disparities in Pacific Islanders/Hawaiian Natives that did not show when data were aggregated. Possible areas of investigation also include mother's insurance information (private/Medicaid), language, race/ethnicity, education, age, and zip code. 2017 (and 2018) LTFU data will be analyzed to look for any trends in these demographic areas. Activities will be determined based on these findings. One specific task will be for Utah EHDI to create culturally sensitive results forms to be distributed to hospitals and midwives and translated into other languages based on need of the region.

WORK PLAN (see Attachment 1) (Criterion 2)

Following are the goals and measurable objectives of this proposal. The specific activities and strategies that will be used are found in Attachment #1.

Goal 1: *To increase by 1% from baseline per year, or achieve at least a 95% screening rate, whichever is less, the number of infants that completed a NBHS no later than 1 month of age.*

Objectives: *Maintain % of infants who are screened prior to 1 month. Increase midwives (OOHB) screening/reporting.* While Utah already maintains an excellent screening rate, we know that there are gaps in the system - babies missed at the hospital, in the NICU and especially OOHBs. Utah EHDI will continue to train hospital screening programs, PCPs and other integral stakeholders in the screening process on the importance of screening prior to discharge. We will also continue to foster relationships with midwives in an effort to increase OOHB screening and reporting.

Goal 2: *Increase by 10% from baseline, or achieve a minimum rate of 85%, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age*.

Objectives: *By March 31st, 2024, increase the number of infants who receive a diagnosis before 3 months to equal a minimum of 85%. Support implementation of health information technology within EHDI programs to improve access to services and reduce time to diagnosis (tele-audiology).* A focus of this goal will be to increase the number of infants diagnosed before 3 months by identifying and remediating gaps (i.e., distance, cost, provider knowledge) in the EHDI system. This may be completed by parent survey, data analysis, etc. In addition, Utah EHDI will continue to provide TAs at two rural/frontier hospitals and educate other frontier hospitals to refer for TA services when available.

Goal 3: *Increase by 15% from baseline, or achieve a minimum rate of 80%, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age*.

Objectives: *By 2024, increase the number of infants enrolled in EI before 6 months of age to a minimum of 80%. Provide educational activities for EI providers. Provide educational activities for Audiologists regarding EI services.* The focus of this goal will be to improve the rate of children enrolled in EI/PIP services before 6 months of age by: meeting with key EI stakeholders (BWEI & PIP) quarterly to address needs, updating BWEI and PIP provider training modules to increase EHDI 1-3-6 knowledge, and update diagnosing audiologists regarding EI and PIP services. New materials will be created to educate Audiologists and families (and even PCPs) on the EI Process. Data will be analyzed to find trends of families not receiving/declining services and/or receiving late services to remedy gaps in the system.

Goal 4: *Increase by 20% from baseline the number of families enrolled in F2F support services by no later than 6 months of age.* ***Objectives:*** *Improve methods of contact and tracking tools for*

F2F support services. Develop and maintain active family engagement and support for families of children identified through newborn hearing screening who DHH. The PC will work with the FL3 to identify ways to provide families with F2F support services and to determine a definition for "enrollment" in F2F services. Resources for F2F support will be updated and the reach will be increased by creating more social media outlets and family engagement on these outlets. We will also work with HT developers to manage data tracking for F2F enrollment services.
Goal 5: Increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age. **Objectives:** *Strengthen capacity to provide family support with children who are DHH as well as adults who are DHH through the EHDI System. Engage families with children who are DHH as well as adults who are DHH throughout the EHDI System.* During this grant cycle, Utah EHDI will continue collaborations with USDB PIP and their Deaf mentor program and investigate opportunities to provide alternate DHH mentor services. Educational events will be held in collaboration with universities and other state resources, all with DHH mentors in attendance.
Goal 6: Increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program. **Objectives:** *Conduct state-level outreach and comprehensive education to stakeholders on the importance of the EHDI system. Identify ways to expand state capacity to support hearing screening in young children up to 3 years of age. Facilitate improved coordination of care and services for families and children who are DHH.* Utah EHDI will continue to present or collaborate with Utah stakeholders, presenting at Grand Rounds, the Utah Speech and Hearing Association, Utah Midwife Organization, AAP as well as provide outreach and education to the school districts/early childhood screening programs regarding family support services. The first 1-2 years of the grant cycle will consist of evaluation of current ECHS protocols and practices and then a plan will be made to expand this infrastructure with EHDI involvement. Initial sites to be targeted include EHS and Part C programs.
Goal 7: Develop and implement strategies for engaging and supporting families from underserved and diverse populations. **Objectives:** *Analyzing data to discover trends and disparities in those who fall short of EHDI milestones*. Utah EHDI data, collected in HT, is individualized data updated by VR. Since the Child Health Advanced Records Management (CHARM) matching rate with VR is 80%, we currently have demographic data on those individuals. With direct access to VR we should be able to fill in the gaps and do an in-depth data analysis of all children who are LTFU at each stage of the EHDI process. Demographic data such as mother's race, ethnicity, income can be used to determine specific outreach activities.

RESOLUTION OF CHALLENGES (Criterion 2, 5)
Any project will not be without challenges. As described previously, Utah does not currently have a H&V Chapter; however, Utah EHDI will again be contracting with UPC/UFV for family support, leadership, and resources (see Letter of Agreement in Attachment #4). Utah EHDI will collaborate with the FL3 center for resources, technical assistance, training, education, QI & evaluation to strengthen infrastructure and capacity for family engagement and support. Because we do not have a H&V Chapter, FL3 has already committed to provide one-on-one training with the Utah EHDI PC and team as needed.

The only Deaf Mentor program in the state is run by USDB PIP. This is a challenge in that they only serve children who are enrolled in their PIP program, and this is only available for 3 years after their initial enrollment with Deaf Mentor services. In addition, Utah EHDI does not yet

have access to records of those children enrolled with a Deaf Mentor. One of the first activities will be gaining that information in order to establish a baseline during year one. For this grant cycle, we also plan to collaborate with DSDHH to investigate opportunities to expand outreach of DHH adult/mentor activities as well as host our own activities in coordination with USDB Deaf Mentors.

A significant challenge to maintaining our OOHB screening rate is that >50% of the units are now out of date (not serviceable by the manufacturer) and need to be replaced. With this funding opportunity, we would purchase new OAE equipment every year to replenish some of these units. We will also be looking at other opportunities such as other grants and multi-unit price discounts.

Buy-in from stakeholders can be a barrier. It has been difficult in the past to recruit physicians (i.e., AAP Chapter Champion, Family Physician) willing to be on our NBHSAC. An idea we will be exploring would be to incentivize an AAP Chapter Champion by paying for their travel to the National EHDI Conference.

In the recent grant period we were able to create a data sharing agreement with BWEI in order to obtain access to their database to review records of infants referred to EI. This is a vital connection to report on the goals of this grant. One limitation is that there is a disconnect between the data reported by PIP and the data reported by EI and we are not sure we are always seeing all of the information, and it appears that there is little communication between the two programs. We will be trying to resolve that by facilitating regular meetings among all three agencies (EHDI, BWEI, and PIP).

Time and resources will always be a challenge. Much time is spent by EHDI staff dedicated to LTFU/D, as well as working with hospitals on QI projects, compliance issues, data quality, and other administrative duties.

EVALUATION AND TECHNICAL SUPPORT CAPACITY (Criterion 3)

Evaluation Purpose: The purpose of this evaluation is to track the achievement of HRSA-20-047 project goals and objectives, including the monitoring of ongoing processes and progress throughout the project.

Stakeholders:

Stakeholder Category	**Interest or Perspective**	**Role in Evaluation**	**How and When to Engage**
Utah EHDI	Overall effectiveness of grant activities	Lead	Ongoing and at all parts of evaluation
NBHSAC	Participants in project	Participants	Throughout project
Birthing Hospitals & Diagnosing Audiologists	Barriers, successful models to timely diagnosis and referral	Participants	Throughout project
USDB PIP/BWEI	Ensuring timely referral and enrollment into EI	Participants	Throughout project

Pediatric healthcare professionals	Engagement and education; increase knowledge of EHDI processes and how to support family of child diagnosed with hearing loss	Participants	Baseline knowledge surveys and learning activities throughout project
UPC/UFV	Provide support for families throughout NBHS, diagnostic processes, as well as support after being diagnosed with hearing loss	Participants	Throughout project
Medical Home/Care Coordination/National Resource Center for Patient /Family-Centered Medical Home	Increasing quality of care/coordination/medical homes for children who are DHH throughout EHDI process	Participants	Throughout project
Other State Agencies (WIC, Early Head Start, DSDHH, OHV)	Effectiveness of timely diagnosis, referral and enrollment	Audience for results	Presentations, educational training, support when issues arise
URLEND	Educational opportunities to increase EHDI knowledge	Participants	Throughout project - didactic training for IPA trainees

Project Background: There are many important facets to this project. Through this funding opportunity, Utah EHDI will improve the timeliness of diagnostic evaluations, decrease the time to EI referral and enrollment, collaborate extensively with a F2F support organization, improve coordination of care for children that are DHH, and increase provider knowledge.

Evaluation Questions:

1. Was the screening rate maintained at the 2017 baseline?
2. What was the increase in OOHB screening/reporting?
3. To what extent was Utah EHDI able to decrease the time to complete diagnostics?
4. What was the overall % increase of newborns and infants who receive timely diagnosis?
5. To what extent was Utah EHDI needs assessment and outreach able to increase knowledge of the importance of the EHDI system? (optional needs assessment funding)
6. What was the overall increase in TA's completed?
7. To what extent did Utah EHDI increase the % enrollment into EI services prior to 6 months of age?
8. How did Utah EHDI ensure family support & engagement with a family-based organization?
9. To what extent was EHDI able to increase EI provider awareness and knowledge?
10. To what extent was EHDI able to provide educational activities for Audiologists regarding EI services?
11. To what extent was Utah EHDI able to coordinate with other agencies (i.e. WIC, OHV, EHS, USDB PIP, DSDHH, FHP, Critical Congenital Heart Defect (CCHD), Utah Birth Defects Network (UBDN), Zika, NBS, ISP, URLEND, etc.)?
12. To what extent was P2P contact increased to families with a child who is DHH?
13. To what extent was adult-to-family support services made available to families with a child who is DHH?
14. To what extent has the EHDI website / social media reach increased/improved?

15. Was a plan created to address diversity and inclusion in the EHDI system?

Evaluation Design:

Tool/Method	Timing	Content/Approach	Responsible Staff
Baseline Data for timely screening	April, 2020	HiTrack/HSFS Survey	Data Coordinator
Baseline Data for timely diagnosis	April, 2020	HiTrack/HSFS Survey	Data Coordinator
Baseline Data for EI	April, 2020	HiTrack, BTOTs	Data Coordinator, PIP Director
EHDI/Midwife Report Cards	Ongoing	HiTrack, BTOTs	Data Coordinator, Audiology Coordinator
Stakeholder Interviews	End of funding period	Randomly select subset of stakeholders to ask more in-depth questions about how initiative was implemented, barriers and supports	EHDI Evaluation Team
Final Reports	End of funding period	Identify extent to which grant goals and objectives were met	EHDI Director / Evaluation Team
Technical Assistance	Ongoing	Track types and amounts of technical assistance provided	EHDI Director, Data Coordinator
Budget	Ongoing	Track expenditures and adherence to grant requirements	EHDI Director, CSHCN Financial (Administrative Services) Manager and Bureau Director

Key Measures/Achievements/Lessons Learned: Utah EHDI will identify key findings, achievements and lessons learned from the evaluation data.
Recommendations and Next Steps: Utah EHDI will address key findings and next steps for the grant goals and objectives, and updated yearly.

Technical Support Capacity (Criterion 3)
Utah EHDI, along with our two contracted organizations, the UPC/UFV and Utah State University, will be monitoring program performance throughout the grant project. All of these teams have extensive experience in program evaluation. As previously reported, grant goals are part of the EHDI program's performance measures for the UDOH and are managed through Google Drive for real-time updates. Progress on these goals are examined at least monthly in team meetings, recorded and discussed, and a monthly report is provided to the Bureau Director. Data is continuously collected from stakeholders throughout screening, diagnosis, EI referral and enrollment, via mandatory statutory reporting and entered into HiTrack, the Utah EHDI-IS (Information System/database) and BTOTS (the BWEI tracking database). Data obtained is from HiTrack and summary reports are generated by the EHDI Data Coordinator and then reviewed.

Each EHDI team member has assigned tasks and roles along with accountability for objective completion and goal attainment. Both quantitative and qualitative data will be collected and reviewed. As goals are SMART, we will know if we are falling short of these time-sensitive goals which will then guide us in the development and completion of QI projects. A potential obstacle of not keeping up the cadence of accountability could be if team meetings come secondary to any current pressing need, e.g. planning the annual EHDI conference or writing required frequent legislative reports. This can be avoided by obtaining buy-in/ownership from all team members so that someone is always moving forward with program/grant performance evaluation even when other members are busy with other urgent bureau tasks. For this and other federal grants, the current EHDI team has successfully completed annual evaluation plans and progress reports, and is confident this will continue if awarded this grant project. Utah EHDI will maintain consistent contact with our HRSA Project Officer by completing quarterly calls, sooner if needed. The Utah EHDI Director has published articles in conjunction with University of Utah researchers evaluating hearing-targeted CMV testing programs in both *Pediatrics*, the *International Journal of Pediatric Otorhinolaryngology*, and *Laryngoscope* (see Attachment #3 Biosketches).

ORGANIZATIONAL INFORMATION (Criterion 3, 5)

The mission of the UDOH is to protect the public's health through preventing avoidable illness, injury, disability, and premature death; assuring access to affordable, quality health care; and promoting healthy lifestyles. Its vision is for Utah to be a place where *all* people can enjoy the best health possible, where *all* can live and thrive in healthy and safe communities. Current strategic priorities are 1) Healthiest People: the people of Utah will be among the healthiest in the country; 2) Optimize Medicaid: Utah Medicaid will be a respected innovator in employing health care delivery and payment reforms that improve the health of Medicaid members and keep expenditure growth at a sustainable level; and 3) A Great Organization: The UDOH will be recognized as a leader in government and public health for its excellent performance, and the organization will continue to grow its ability to attract, retain, and value the best professionals and public servants. Utah EHDI is housed in the CSHCN Bureau within the UDOH's Division of Family Health and Preparedness, where the state MCHB (Title V) also resides. Some of CSHCN's programs and work are supported by Federal Title V funds allocated to help address the needs of children and youth with special health care needs and their families. In Utah, this Block Grant support does not extend to the EHDI programs. Part of the EHDI sustainability plan is seeking out and securing some funding through these Title V funds. The mission of the CSHCN Bureau is to improve the health and quality of life for children with special health care needs, and their families, through early screening and detection, data integration, care coordination, education, intervention, and life transitions. CSHCN provides and promotes family-centered, coordinated care and facilitates the development of community-based systems for these children and their families. CSHCN activities focus on reduction of preventable death, disability and illness in children due to chronic and disabling conditions. Specific bureau goals include: All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home; will have adequate private and/or public insurance to pay for the services they need; all children will be screened early and continuously for special health care needs; services will be organized in ways that families can use them easily; families will partner in decision making at all levels; all youth with special health care needs will receive

the services necessary to make appropriate transitions to adult health care, work, and independence.

As you can see from the attached Organization Chart (Attachment #5), all three of the Utah state mandates involving audiology (EHDI, CMV, and CHAP) are housed in the CSHCN Bureau. Led by Noël Taxin, MS, since 2014, the CSHCN bureau also holds the following programs: UBDN; CCHD Screening; Zika Surveillance, Intervention, and Referral; BWEI; FHC; Autism System Development; CHARM; and the Kurt Oscarson Children's Organ Transplant Fund. Being in the same bureau and located geographically next to each other allows for close collaboration amongst the programs. CSHCN has an EHDI Medical Director who provides medical oversight for the three EHDI programs, including provision of the state order for ABR and CMV testing when required after failed NBHS. Within the UDOH, we have access to many important programs and services that will help support the provision of culturally and linguistically competent and health literacy services. These include the Office of Health Disparities, Center for Multicultural Health, the Bureau of American Indian/Alaska Native Affairs, and the Office for Public Information and Marketing. We have a very strong EHDI team that has many years of experience, including working with each other as exemplified by the Project Director, EHDI Data Coordinator, and EHDI Audiology/Compliance Coordinator being team members together for almost a decade. All of these elements contribute to Utah EHDI's ability to conduct the grant project requirements and meet program expectations. As aforementioned, grant objectives and progress are program performance measures not just for this federal funding but also for UDOH and are closely tracked with Google Drive spreadsheets for real-time updates by all team members. Grant spending is monitored by the EHDI Director, Bureau, Division and Department Financial Managers. Both employee and contracted EHDI team members enter time daily along with detailed information on tasks accomplished. Time charged is reviewed weekly by management for employees; bi-weekly for UPC contractor; and quarterly for USU contractor. Other budget line items (e.g. travel, equipment, interpreting) need to be signed off and approved by the same group mentioned above. Also, a Grant Monitoring folder in the UDOH share drive is updated by the EHDI program manager to document grant monitoring activities with our contractors; this folder is regularly audited by upper management.

As previously mentioned, Utah EHDI collaborates with many different partners statewide with key partners solidifying their support of grant project goals as evidenced in Letters of Support, Attachment #7. Utah EHDI has a proven record of facilitating partnerships with stakeholders including service providers and health professionals, as well as, increasing family engagement significantly in this current grant project. Utah EHDI works with many different stakeholders with a variety of unique needs, which can overlap with other challenges. For example, American Indians in southeastern Utah not only have challenges with access due to cost, distance and availability of specialists, there is often the inability to reach them via phone due to often using disposable phones, and their homes typically do not have a physical address, but a description "between mile marker 1 and 2, the blue house with the tan roof" - once the family has been discharged, it is very difficult to reach them for important follow-up. We partner with the UDOH Indian Health program and the UNHS to not only provide culturally appropriate health education materials, but also to assist in follow-up with families when possible. Utah EHDI will continue to reach out to organizations that serve these unique populations and strive to improve services statewide.