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## PROJECT NARRATIVE

### Introduction

In 2017, 96% of eligible infants in South Dakota (SD) were screened for hearing loss<sup>1</sup>. Despite this relatively high screening rate, the SD Early Hearing Detection and Intervention (EHDI) Program recognizes diagnostic and intervention rates need to be increased throughout the state. Through the current proposal, the SD EHDI Program defines plans to extend efforts begun under previous grant periods to initiate new efforts to target the number and timeliness of diagnostic audiologic evaluation and referral to early intervention for young children. Additionally, a new effort will be increasing awareness of the need for hearing screening for children up to three years of age.

In 2015, the newly formed partnership between the South Dakota Department of Health (SD DOH) and the University of South Dakota (USD), which came to be known later as the SD EHDI Collaborative, allowed the first HRSA grant to initiate quality improvement activities within the SD EHDI Program. The collaboration will continue for the duration of the proposed grant program. New and existing partners will also contribute to the achievement of the grant activities.

During the grant-funding period of April 2020 through March 2024, the purpose of the project is to support the enhancement of EHDI statewide program. The SD EHDI Program will ensure that deaf or hard-of-hearing children in SD are identified through newborn, infant, and early childhood hearing screenings and receive diagnosis and appropriate early intervention to optimize language and vocabulary development, receptive language, expressive language, and social-emotional development.

The proposed project will focus on four goals in order to accomplish the project goal:

**Goal 1:** Provide a coordinated infrastructure to increase the hearing loss screening of infants by one month of age from a baseline of 98% (2017)<sup>1</sup> to 99% (projected 2024). Increase diagnosis by three months of age from a baseline of 16% (2017)<sup>1</sup> to 25% (projected 2024). Increase the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age from baseline 15% (2017)<sup>1</sup> to 23% (projected 2024). Create an infrastructure to expand capacity to support hearing screening in young children up to 3 years of age.

**Goal 2:** Engage and educate health professionals and service providers in the EHDI system. Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.

**Goal 3:** Strengthen the statewide capacity to engage and support families with children who are deaf or hard of hearing.

**Goal 4:** Facilitate improved coordination of services for children who are deaf or hard of hearing through a formal agreement for communication, referrals, and data sharing between the South Dakota EHDI Program and the South Dakota Department of Education early childhood programs.

## **Needs Assessment**

### South Dakota

South Dakota (SD) has more than 77,000 square miles of land<sup>2</sup>, and it is the home of approximately 882,235 residents; averaging 10.7 persons per square mile. The State is comprised of 66 counties, ranging in population from 928 residents to 192,876 residents. There are nine SD counties with more than 20,000 residents. Two of these metro areas, Sioux Falls and Rapid City, are located 347 miles apart but together contain three urban counties and 41% of the population. The other urban counties comprise 20% of the SD population. The rural counties comprise 27% of the SD population, and the sparsely populated frontier counties hold 12% of the State's population.<sup>3</sup>

There are nine federally recognized Indian tribes within the SD borders, and 9% of the State's total population is American Indian. In 2018, 84.4% of the population was Caucasian with all other racial groups comprising 6.6%. American Indians comprise 1.7% of the total United States; in comparison, American Indians comprise 8.9% of SD's population. The birth rate of the American Indian population is 1.5 times that of the general United States birth rate. The median age of SD American Indians is 22.9 years; in comparison, the overall median age of the SD population is 37 years.<sup>34</sup>

According to 2018 population data, 84.4% of the population was Caucasian with all other racial groups including Black and Asian comprising 6.6%. In 2018, 24.7% of the state's population are children (under the age of 18) while 7% are age 4 or younger. Roughly 37% of the State's female population is childbearing age (age 15 through 44). In 2017, there were 12,032 resident births and 12,551 estimated pregnancies.<sup>3</sup>

SD has 49 general community hospitals, 38 of which are critical access hospitals. There are five federally qualified health centers with 32 delivery sites and 60 rural health clinics. There are five Indian Health Services (IHS) hospitals in SD, two of which provide routine obstetrical services.<sup>5</sup>

### Rurality

The rurality of SD, healthcare provider shortage, and lack of access to services contribute to the high Loss to Follow-Up / Loss to Documentation (LTF/D) rates in the State, as families may not have the services available in their area for rescreening, diagnostic testing, and intervention. In SD, it is not unusual for a family to travel over 150 miles by car to access tertiary health services. Travel demands are further compounded by limited resources due to high poverty rates and weather conditions that prohibit or increase the risk associated with travel. The geographical distance in the State, along with the winter road conditions, may deter parents from completing a timely follow-up of their newborn's hearing health. Rurality and lack of access to care limit continuity of care and follow-up that are compounded by those challenges imposed by the high poverty rates. Limited funding and specialty services, as well as lack of culturally sensitive programs that are accessible to mothers and infants living in remote rural areas, are barriers to follow-up. SD EHDI has noted many of the infants who are LTF/D are from rural counties that lack access to tertiary care centers or are from areas that are identified as critical access hospitals that lack specialty care. In addition, LTF/D is the highest among infants born to American Indian families and infants born to low income families living in the western and middle region of the State. Another factor to consider is transportation to access services. For some, this means traveling over 50 miles to see a primary care provider and even further to see a specialist. Most specialists and the two children's hospitals are located on the eastern side of the State. This adds additional travel and expense for families of children in the central and western regions of the state. On Indian reservations, this problem is further complicated by the lack of a reliable transportation system.

### Poverty

A major factor that impacts SD's follow-up rates and access to care is high poverty levels across the state. According to the latest 2013-2017 U.S. Census, the median household income in SD is \$54,126. The percentage of people at poverty level is approximately 13%. The 10 poorest counties in SD are either part of or adjacent to one of nine American Indian reservations, with poverty levels from 22.3%-48.6%. Overall, 10.7% of South Dakotans were uninsured.<sup>3</sup> In 2017, 6.2 percent of SD children were uninsured. States like SD, with larger American Indian populations, have higher rates of uninsured children than the national average.<sup>6</sup>

#### Immigrant and Refugee Population

Over the past few years, SD has witnessed an increase in the number of African refugees. SD ranks one of the highest states in the percentage of African born among its immigrant population. The total immigrant population in SD is 24,000. In Sioux Falls alone, the immigrant population is about 11,000 people, which is about 17% of the total foreign-born population. In 2017, Lutheran Services helped settle 389 refugees in Sioux Falls and 146 in Huron. In 2018 another 209 refugees were settled in Sioux Falls. The five countries most commonly represented in SD's 2018 settled refugee population are from Bhutan, Eritrea, the Democratic Republic of the Congo, Ukraine, and Burma. The majority of those immigrants are of childbearing age with 55.8 % of foreign born being 18-44 (median 34.2) years old and of those, 47.1 % are females.<sup>78</sup> There is paucity of data on the needs of this new segment of SD's population regarding hearing loss.

#### Professional Shortage

Approximately two-thirds of the State is designated by the federal government as a Health Professional Shortage Area (HPSA). As of June 4, 2019, there were 4,442 physicians and 654 physician assistants licensed in the state. In addition, there were 1,140 actively licensed nurse practitioners and 34 actively licensed nurse midwives in SD. As of October 10, 2019 there were 87 audiologists licensed in SD.<sup>9</sup>

#### Limited Access

In SD, there are 14 self-identified pediatric audiology facilities. Of the fourteen, five have reported having the equipment necessary for comprehensive pediatric audiology diagnostic testing. Of these five, two have reported the capability to offer sedated Auditory Brainstem Response (ABR). Four identified pediatric audiology diagnostic sites are in the Southeastern portion of the state, with one location on the far western side of the State. Limited audiology services are available in the central and western regions of the State. The SD EHDI program last updated the list of audiology screening and diagnostic sites in 2019.

### **Methodology**

**Goal 1: Provide a coordinated infrastructure to increase the hearing loss screening of infants by one month of age from a baseline of 96% (2017)<sup>1</sup> to 97% (projected 2024). Increase diagnosis by three months of age from a baseline of 16% (2017)<sup>1</sup> to 25% (projected 2024). Increase the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age from baseline 15% (2017)<sup>1</sup> to 23% (projected 2024). Create an infrastructure to expand capacity to support hearing screening in young children up to 3 years of age.**

The SD EHDI Collaborative expects to achieve by 2024 the targets presented in Table 1, using the 2017 CDC EHDI Screening and Follow-up Survey data as baseline, and the targets presented in Table 2, using grant Year 1 data as a baseline.

**Table 1. Expected 1-3-6 outcomes for the South Dakota EHDI Collaborative after 4 years of project implementation.**

Objective	Baseline (2017 CDC)	Increase	2024 Goal
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 complete a newborn hearing screen no later than 1 month of age.	12,009 infants with a screening pass before 1 month of age + 248 infants with a screening did not pass before one month of age = 12257 / 12813 total live births = 96%	1%	97%
Increase by 10 percent from baseline, or achieve a minimum rate of 85 percent, the number of infants that complete a diagnostic audiological evaluation no later than 3 months of age.	17 infants with no hearing loss identified before 3 months of age + 27 infants with hearing loss identified before 3 months of age = 44 / 270 infants did not pass most recent/final screen = 16%	10%	26%
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.	3 infants enrolled (signed IFSP) before 6 months of age / 37 infants diagnosed with permanent hearing loss = 8%	15%	23%

**Table 2. Expected family support and training outcomes for the South Dakota EHDI Collaborative after 4 years of project implementation.**

Objective	Baseline (April 1, 2020-March 31, 2021)	Increase	2024 Goal
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.	Anticipated 4 or more families will enroll in the first year.	20%	Five or more families enroll each year.
Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.	Anticipated 4 or more families will enroll in the first year.	10%	Five or more families enroll each year.
Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.	Increase by 10% based on the number of providers trained the first year.	10%	

The following activities will be deployed to obtain the above objectives.

**Activity 1. 1. Expand SD’s teleaudiology infrastructure.**

The continuation and expansion of teleaudiology started as a pilot program with funds from the prior grant cycle. The successful expansion of teleaudiology across SD will achieve a coordinated infrastructure, which ensures that infants meet 1-3-6 recommendations and reduce loss to follow-up/loss to documentation.

**Task 1.1.1: Work with the SD Department of Social Services (DSS) to obtain Medicaid insurance coverage for teleaudiology.** SD remains one of the few states without Medicaid reimbursement for teleaudiology. The SD DSS Medicaid Medical Director, who is on the Advisory Board, has provided some insightful information on this process. During the prior grant cycle, supporting information was collected on teleaudiology coverage in states across the country, as well as which telemedicine services are currently covered in the state. Coverage of services needs to be ensured before opening the program to other audiologists. Otherwise, many audiologists will not utilize the program. Feedback from parents whose children used the teleaudiology services during the pilot will be beneficial to justifying its expansion.

**Task 1.1.2: Establish at least one additional teleaudiology site (from baseline two).** In the pilot phase (2018 – 2019), a location in the central part of the State was pursued but did not come to fruition due to several factors. The SD EHDI program will work with providers to provide teleaudiology training and form partnerships that will contribute to the development of teleaudiology practice. Successful expansion will include the further development and creation of tool kits and resources for use by remote sites, as well as training and retraining materials including videos. The teleaudiology program is currently piloting an alternative video connection at the two sites to gain information for when the teleaudiology program becomes available across the state of SD.

**Task 1.1.3: Mitigate no-show teleaudiology appointments.** A high rate of “no shows” was recognized during the pilot phase. An initial inquiry led to reports of complications with travel to the appointments. Reasons for “no shows” will be further evaluated during this grant cycle. From the insight gained a strategy will be developed to minimize “no show” appointments. Assistance for transportation services in different area locations of the state is being explored for future teleaudiology patients to address travel concerns.

**Task 1.1.4: Continuously improve teleaudiology by incorporating patient feedback into operations.** Develop a survey process for families, referring clinicians, and audiologists. Any collection methods used to obtain feedback from families and providers that refer to or utilize teleaudiology services will first be Institutional Research Board (IRB) approved.

## **Activity 1.2. Coordinate screening efforts for young children from birth up to three years of age.**

Coordinating and increasing awareness of existing screening for children up to three will take place with many partners conducting these screenings.

**Task 1.2.1: Deploy mobile hearing screening units.** SD School for the Deaf (SDSD) has two mobile hearing screening and testing units, one on each side of the state. Each travel statewide and visit schools upon request. SDSD publishes and distributes a calendar of all the locations they will visit during each academic year. Caregivers or service providers in these locations can arrange for their non-school age child to have testing completed at the mobile unit when it is nearby. The mobile unit can also go to daycares and preschools to provide screenings when requested. Additionally, when schedules allow, the audiologists frequent local daycare centers to provide hearing screenings. In addition, SDSD provides no-cost testing to any child in the State with whom there is a concern of hearing loss. This service is provided at both the Sioux Falls and Rapid City SDSD audiologic locations. Grant efforts will help raise awareness and use of these services.

**Task 1.2.2: Increase hearing screenings through Early Head Start and Birth to Three programs.** The SD EHDI program will create a Memorandum of Understanding (MOU) with SD DOE to ensure screening are occurring when needed and per guidelines, as well as being offered when caregivers have concern regarding hearing status.

**Task 1.2.3: Use a graduate student outreach program to screen children in daycare centers.** USD Department of Communication Sciences and Disorders has an existing program, Kid Screen, in which graduate students visit daycare centers providing speech, language, and hearing screenings for preschoolers. Kid Screen visits also offer awareness to daycare staff about the importance of hearing screenings for young children under the age of three. This grant activity will work alongside these efforts and relationships. Concise materials will be created that will be shared at daycares with common risk factors and signs to be aware of for delayed onset hearing loss. These materials will also include resources for concerned parents and caregivers if they believe a child may need a screening.

**Task 1.2.4: Augment existing diagnostic evaluations with hearing screenings.** The USD Center for Disabilities LEND Program clinics provide comprehensive audiology evaluations as a component of their interdisciplinary diagnostic evaluations for Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, and general Developmental and Behavioral concerns.

**Activity 1.3. Assess access to hearing screening equipment for high loss to follow up/loss to documentation populations in the state.**

**Task 1.3.1: Conduct a review and create an action plan with birthing hospitals that have high LTF/d.** Determine if they have working equipment or a back-up plan in the case of failed equipment. Create an action plan with the hospitals to develop a plan to screen 100% of infants and establish referral plans.

**Task 1.3.2: Create an action plan with home birth midwives to ensure they have the appropriate hearing screening equipment access.** Collaborate with the midwife association, SD Birth Matters to develop an action plan to purchase mobile testing units or gain access to existing equipment. Create an action plan with SD midwives to screen and/or refer 100% of infants and establish referral plans.

**Task 1.3.3: Create an action plan with Indian Health Services (IHS) to ensure their sites have the appropriate hearing screening equipment access.** Pine Ridge, one of nine tribal nations in SD, currently has no working hearing screening equipment, but it is one of the higher frequencies IHS birthing facilities. A partnership with SDSD, which provides services on reservations and has outreach consultants working with American Indian populations, will further build this relationship. The IHS facilities reported difficulty of families attending follow up appointments after hospital screening referrals due to inadequate transportation. Determine if traveling equipment for use at home visits is appropriate for families in locations outside of the towns.

**Activity 1.4. Assess and modify EVRSS to expand data collection and reporting.**

**Task 1.4.1: Assess and modify SD DOH statewide Electronic Vital Records Screening and Surveillance (EVRSS) to expand data collection and reporting for hearing screening for children up to age 3.** For EHDI goals and objectives beyond the 1-3-6 components (late onset hearing loss, risk factors, NICU stays, etc.), EVRSS will need significant modifications to capture EHDI data children who are older and for those born outside of SD.

**Activity 1.5. Complete an assessment of current partnerships and identify key partners.**

**Task 1.5.1: Complete an assessment of current partnerships and identify prospective key partners to address gaps in the EHDI system.** Partners may include, but are not limited to, health professionals, service providers, birthing centers, state or territory organizations and programs, and any others who could help address gaps. Maintain and strengthen partnerships that could help address gaps in the EHDI system. Establish new partnerships that could address gaps in the EHDI system.

Current partnerships will be assessed by reviewing all member organizations of current and past advisory boards, learning communities, communities of practice, organizations that do or have held agreements with the Collaborative, and organizations to which the Collaborative has provided trainings. New key partners will be identified by reviewing if any of the partner organizations within our existing partnership can be leveraged, such as the SD Department of Education's Interagency Coordinating Council. Some groups we anticipate building new partnerships will include the newly formed SD Hands & Voices Chapter and the SD Department of Education's Early Learning Office, which houses the Birth to Three and Head Start Programs.

**Activity 1.6. Continue and restructure the SD EHDI Advisory Board.**

**Task 1.6.1: Maintain and restructure the existing SD EHDI Advisory Board, to ensure 25% caregiver of DHH children representation and to meet the current proposal guidelines.** Advisory board restructure will be achieved by retaining active participants from the current Advisory Board and Learning Community. Community professionals recruited will include pediatric audiologists, speech language pathologists that work with young children, home birth midwives, pediatricians, and family practice providers. As referenced in the Needs Assessment – Professional Shortage section, SD relies on nurse practitioners as primary care providers in many rural areas. For this reason, The Nurse Practitioner Association of South Dakota will also be contacted for representation on the Advisory Board.

**Task 1.6.2: Advisory Board meetings will be held twice a year.** The Advisory Board will provide feedback and guidance on how to achieve the proposed program goals and objectives.

**Activity 1.7. Develop a plan to address diversity and inclusion in the EHDI system.**

**Task 1.7.1: Develop a plan to address diversity and inclusion in the EHDI system by working with partners to reach rural, American Indian, immigrant, and low Social Economic Status (SES) populations across the State.** The SD EHDI Collaborative makes efforts to include culturally and linguistically diverse programs, community leaders, families, informal community leaders, and non-traditional partners. Throughout the project, the USD American Indian Cultural Center staff have proven a wealth of knowledge in providing connections to individuals who have provided interpretation services of EHDI materials into Lakota and Dakota languages. The current Advisory Board membership includes an IHS consultant who helps facilitate trainings in IHS facilities across the state. Meetings have been held with members of American Indian communities across the State in order to determine what works best for their community members and how to address the EHDI process in a culturally sensitive manner. Communications have just begun with a clinic that serves a culturally diverse population, including recent immigrants and refugees, on how to ensure EHDI messages for parents and families are directed appropriately.

**Activity 1.8. Maintain, develop, and promote EDHI webpages.**



**Task 1.8.1: Continue to maintain the SD DOH Newborn Hearing Screening Program (NHSP) webpage as a resource center.** Maintain resources for healthcare providers and families, while developing resources for service providers and care providers.

**Task 1.8.2: Maintain and develop links to and from other resource websites in the State and across the country.** Review the SD DOH NHSP and USD EDHI websites yearly for any required updates to ensure material and resources remain valid.

**Task 1.8.3: Establish an EHDI webpage within the USD website in order to actively update and highlight EHDI activities.** Make the site a resource not only for parents and healthcare professionals but also others service providers who work with DHH infants and children, child care providers to increase awareness of hearing loss, and students pursuing academic studies in which they may have a career working with children to create awareness of hearing loss.

**Goal 2: Engage and educate health professionals and service providers in the EHDI system. Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.**

**Activity 2.1. Conduct outreach and education statewide to health professionals and service providers regarding the 1-3-6 recommendations and the need for hearing screenings up to age three via presentations and trainings.**

**Task 2.1.1: Create a list of health professionals and tracking system.** Targeted providers will include birthing center screeners, home birth midwives, family medicine and pediatric providers, pediatric audiologists, ENTs, and early childhood providers.

**Task 2.1.2: Create and update an EHDI curriculum to educate providers.** Per guidance with the National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH), the SD EHDI will create a comprehensive curriculum for providers. The AAP SD Chapter EHDI Champion has worked with the Collaborative in past grant cycles by providing presentations and virtual (ECHO) sessions on hearing loss related risk factors and genetic components. Leadership Education in Neurodevelopmental and Related Disabilities (LEND) in the State will provide hearing screening training to its cohorts of trainees. These trainees span a wide range of disciplines from medicine to audiology to physical and occupational therapy. Curriculum components will include:

- ***Birthing center and midwife*** trainings may cover the following topics:
  - Types of hearing screenings and how they are properly conducted;
  - Refresher courses on screening techniques;
  - Reporting processes;
  - Importance of reporting results and referrals to the SD DOH to ensure complete statewide EHDI data; and
  - cCMV (cytomegalovirus) protocol process.
- Sessions specifically for ***pediatric audiologists*** will focus on the importance of reporting results and referrals to the SD DOH to ensure complete statewide EHDI data. Based on anecdotal evidence, many audiologists believe that by checking the “referral box” on the SD EHDI data reporting form that they initiated the referral to birth-to-three. Actually, checking this box indicates that the audiologist has already made the referral. In addition, audiologist education about obtaining parent consent to find out if a child who was referred to Early Intervention was enrolled is needed; this is because SD Department of Education (DOE) does not currently share information with DOH.

- ***Family practice and pediatric providers*** will be invited to sessions which may address:
  - Importance of reporting audiologic testing results to the SD DOH to ensure complete statewide data;
  - Importance of infants and young children seeing pediatric audiologists for best results;
  - Locations of pediatric audiologists and teleaudiology sites;
  - Genetics and genetic tests involved in hearing loss; and
  - Risk factors for delayed and progressive hearing loss in young children.Content experts for these sessions may include the SD EDHI program coordinator, pediatric audiologists, and the AAP SD Chapter EHDI Champion.
- All providers will receive trauma-informed care. In conjunction with the Center of Disabilities and the Center for the Prevention of Child Maltreatment (CPCM) at USD, sessions will be held for healthcare and services providers regarding how individuals with disabilities are more likely to suffer from abuse, neglect, violence.

**Task 2.1.3: Create and update a list of health professional and service provider groups and conferences.** Examples include but are not limited to the South Dakota Speech Language Hearing Association, Nurse Practitioner Association of South Dakota, South Dakota Physicians Association, South Dakota Public Health Association, and Midwest Deaf Education Conference.

**Task 2.1.4: Conduct grand rounds and provide access to recordings of presentations at all three integrated hospital systems.**

Health systems include Sanford Health, Avera, and Rapid City Regional Health.

**Task 2.1.5: Leverage Project ECHO (Extension for Community Healthcare Outcomes) to deploy provider education.** Project ECHO was implemented with funds from the last HRSA EHDI grant cycle. Overcoming the obstacles of distance and locally unavailable expertise is the objective of the ECHO model, a videoconferencing case-based learning platform that can feed a knowledge-sharing network. Project ECHO, through a hub and spoke model, leverages technology to amplify knowledge in order to support underserved populations through their providers and educators. USD was one of the first hub locations in SD. ECHO sessions are geared toward several types of providers are planned with a wide variety of topics, such as referenced above.

**Task 2.1.6: Partner with daycare and early childhood associations and service providers to provide training to daycare professionals.** In daycare settings, awareness and training topics will focus on several pertinent subjects. One will be regarding the seriousness of the spread of CMV to pregnant women and staff. When a pregnant mother obtains CMV, it can cause neonatal complications, such as hearing loss at birth or developed hearing loss in young childhood. Concise sessions will stress that good hygiene can be the best way to prevent the spread of this virus. Additional topics will include the risk factors for delayed onset hearing loss, development milestones to watch for signs of hearing loss, and the importance of hearing screenings for children up to three years of age if a caregiver or parent has concern. The USD School of Education will serve as an insightful partner. The School houses a local Early Head Start program, as well as a children's care center.

Additional educational topics may be determined by the optional needs assessment, if awarded.

**Goal 3: Strengthen the statewide capacity to engage and support families with children who are deaf or hard of hearing.**

**Activity 3.1. Engage families throughout all aspects of the project.**

**Task 3.1.1: Ensure 25% representation of families and caregivers of DHH children on the Advisory Board.**

**Task 3.1.2: Identify, recruit, and invite caregivers of DHH children to attend meetings, trainings, and other events.** Provide grocery or gas gift cards to parents who attend Advisory Board, Project ECHO sessions, and other meetings to compensate for their travel costs. Travel reimbursement has not been provided in the past but will be during this grant cycle to acknowledge the time and resources parents spend contributing to EHDI efforts.

**Task 3.1.3: Develop, maintain, and promote the EHDI136 webpage as a resource center for healthcare providers, service providers and families.** An EHDI web domain was secured with funding from the last grant cycle and will be further developed to provide an engaging opportunity for parents to be involved in the steps of the 1-3-6 EHDI guidelines. The first component that was developed and launched is a web-based mobile application that walks parents through the 1-3-6 guidelines for screenings and follow-up to identify infants at risk for newborn hearing loss. The application also assists parents in tracking developmental milestones for their child based on the child's date of birth. Aggregate data is collected regarding usage of the web-based application. This data will continue to be collected and analyzed for insight into how the site can be advertised to the most pertinent populations. To this point, the data has indicated that users often access the site from often visited and trusted sites in the state, like those of the DOH and SDSO, as well as the Facebook posts from these organizations. With this knowledge, grant activities will focus on increasing the number of partner websites and posts where the website link can be found. Additionally, the EHDI136 site will be developed to include many other resources for parents, including events occurring in the state.

**Task 3.1.4: Sponsor a parent leader to attend the annual EHDI Conference.** Parent leadership opportunities will be offered via a sponsorship for a parent each year to attend the Annual EHDI Conference.

**Activity 3.2. Build relationships with minority populations with the aim to increase screening, referrals, and follow-up.**

**Task 3.2.1: Establish a part-time EHDI family support diversity liaison.** The family support diversity liaison will lead efforts to build relationships with minority populations. These groups will include American Indians, and immigrant and refugee populations from Africa and Asia, as well as Spanish speaking groups. Many other USD and School of Health Science faculty will provide insight on increasing awareness of and determining barriers to high LTF/D rates in some populations.

Dr. Sabina Kupersmidt, an Assistant Professor of Nursing and Chair of the Interprofessional Health and Education Center (IHEC), who will serve as the family support diversity liaison, has existing connections to immigrant groups in the area. For example, she previously conducted a health needs assessment of African immigrants in collaboration with the pastor from Zion Lutheran Church in Sioux Falls. Her findings from this student-led project were presented at the 2019 MNRS meeting in Kansas City<sup>10</sup>. The same health needs assessment was conducted in Spanish with a population of Mexican immigrants at a Spanish-language church. Dr. Kupersmidt is also a board member of the

Buddhist Society of South Dakota that draws membership from Nepalese and Bhutanese immigrants. She has access to immigrants from India through her membership at the Hindu Temple of Siouxland, where she teaches a weekly yoga class.

**Task 3.2.2: Leverage Advisory Board members and other professional relationships to build inroads into tribal nations.** Trainings have occurred at Pine Ridge, Lower Brule, Crow Creek, and Rosebud at IHS facilities. A key Advisory Board member, Captain Suzanne England DNP, CNM, CFNP, PMHNP is the IHS Great Plains Area Maternal Child Health Consultant for the tribal nations in North and South Dakotas, Iowa and Nebraska. She is triple boarded as a certified nurse midwife, family nurse practitioner and a family psychiatric nurse practitioner. She has assisted in creating connections with IHS facilities for grant activities.

**Activity 3.3. Conduct outreach and education to inform families about opportunities to be involved in the state EHDI system.**

**Task 3.3.1: Conduct outreach and education to inform families about opportunities to be involved in different roles within the state EHDI program.** Opportunities include Project ECHO parent sessions and the expansion of the EHDI136.com website, social media, and other communication platforms.

**Task 3.3.2: Conduct parent and caregiver education via Project ECHO.** Project ECHO sessions for parents will include outreach and education on a number of topics. One session will focus on the seriousness of the spread of CMV to pregnant women, as when it is obtained by a pregnant mother it can cause neonatal complications, such as hearing loss at birth or developed hearing loss in young childhood. The material will stress that good hygiene can be the best way to prevent the spread of this virus. Additional topics will include the risk factors for delayed onset hearing loss, development milestones to watch for signs of hearing loss, and the importance of hearing screening for children up to three years of age if a caregiver or parent has concern.

**Task 3.3.3: Conduct trauma-informed prevention and response training.** With the Center for Disabilities, CPCM will provide training on how individuals with disabilities, including those with hearing loss, can be more likely to suffer from abuse, neglect, and violence.

**Activity 3.4. Support family engagement and family support activities via programs and activities that provide direct family-to-family support services and DHH adult-to-family support services.**

**Task 3.4.1: Review other successful parent-to-parent counseling models used across the state by other institutions to see what can be replicated.** One such program is the WIC breastfeeding peer counselor model. Conduct a gap analysis and develop an action plan.

**Task 3.4.2: Support and raise awareness of existing family support organization activities.** Support and raise awareness of existing family support organization activities, such as a monthly family-to-family social groups for children ages birth to 5, annual education events, annual holiday carnival events, and annual picnics. Some school districts only have one DHH student, which can cause families to feel isolated. In order to relieve feelings of isolation, SDSO Outreach consultants arrange social events throughout the year in Sioux Falls, Watertown, Pierre, Vermillion, Yankton, and Rapid City for families with DHH children. Determine feasibility of expansion of existing programs, such as shared

reading, where a deaf adult mentor takes a bag of books and materials to a young child's house to sign and read to child typically aged birth to five.

**Task 3.4.3: Establish adult-to-family connections.** SDSD contracts with Communication Services for the Deaf (CSD) deaf adult staff to act as mentors. Within two months of connecting with a SDSD consultant, the consultant gets the family connected with a DHH adult. CSD locations in Sioux Falls, Aberdeen, and Rapid City have received federal funding from HHS to restart the deaf mentor program. Along with those trained by parent connection, five more adults will be trained. CSD will train four adults for the deaf mentor program. CSD will work with SDSD on the deaf mentor program via a MOU.

**Goal 4: Facilitate improved coordination of services for children who are deaf or hard of hearing through a formal agreement for communication, referrals, and data sharing between the South Dakota EHDI Program and the South Dakota Department of Education early childhood programs.**

**Activity 4.1. Engage the SD DOE in the development of a written MOU of communication and data sharing with the SD DOH.**

**Task 4.1.1: Engage the SD DOE in the development of a written MOU of communication and data sharing with the SD DOH in order to improve coordinator and care services across early childhood programs, such as the Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.** Many state EHDI programs have had success working with their State's Education Departments. For example, New Mexico has developed a boilerplate MOU that has been used successfully in part by at least nine other states. This precedence, along with the offered assistance from successful states, will be helpful in engaging the SD DOE in this process. The relationship SDSD has with the SD DOE and SD EHDI program will aid to bridge this process.

**Task 4.1.2: Review SDSD and SD DOE data sharing process and develop a plan of how SD EHDI can provide direct referral information to SDSD.**

### ***Resolution of Challenges***

The SD EHDI Collaborative anticipates challenges as the team continues to work on developing a statewide EHDI system of care. The following section discusses those challenges and offers corresponding solutions to mitigate the potential problems that may occur.

**Challenge 1: Distance and weather present a significant barrier to travel as a rural state in the Northern Plains.** The distance between the SD EHDI Collaborative partner USD in Vermillion to the SD DOH in Pierre is 203 miles. The distance between the state's two largest cities, Sioux Falls and Rapid City, is 347 miles, which can make visits to specialists and major healthcare centers prohibitively far away for some populations. Winter weather conditions and long distances could be barriers to the Advisory Board, the team meetings, and scheduling training sessions.

In a vast, weather-variable state like SD, in-person meetings can be difficult to arrange but are well worth the effort. When in person for a meeting, people are more engaged in the conversation and less likely to be multitasking, as compared to a conference call. Meetings are best for observing body language and other indicators of meaning, leading to fewer misunderstandings and miscommunications.

Resolution: There are a variety of technologies that can be used with the current proposal to overcome the barriers of distance and severe weather. The use of teleconferencing, Skype/online

call-in methods, and videoconferencing capabilities are some of those methods that can be used to mitigate these barriers. USD and the Department of Health use the same Distance Network, and members of the SD EHDI Collaborative are comfortable working with these different methods of technology.

**Challenge 2: Obtaining Early Intervention (EI) data has been challenging in the previous HRSA grant cycle as demonstrated by baseline measures.** The current process is facilitated by the diagnostic audiologist at the time hearing loss has been identified. Signed parent authorization is required for the Birth to Three Connections Program (Part C) to release the enrollment and eligibility information to the SD EHDI Program. Audiologists have been inconsistent with assistance, reporting a failure to remember or a misunderstanding of the purpose and intent.

Resolution: Audiology training, care coordination, and implementation of an Individualized Family services plan as well as MOUs and consent for release of information will address this challenge. A MOU and collaboration with SD Early Intervention Program Birth to Three will allow for early referral and intervention, as well as care coordination. Collaboration with Early Head Start and Women, Infants, and Children (WIC) will allow educational support for parents and providers to ensure care coordination and timely referral, as well as identification of late-onset hearing loss.

**Challenge 3: The SD EHDI Collaborative recognizes that there may be cultural and trust barriers to working with the American Indian population.** In past work efforts, it has been challenging to receive timely feedback from the reservations regarding initiatives for various reasons that are unknown.

Resolution: The SD EHDI Collaborative recognizes that it takes time to develop relationships and trust with different organizations across the state. The SD EHDI was successful through the previous funding in establishing strong relationships with Captain England, Maternal Child Regional Consultant for the Indian Health Services. She is a nurse practitioner and serves on the SD EHDI Advisory Board and the Learning Community. Through Captain England, SD EHDI was able to provide training to the two birthing facilities within the Indian Health Service that serve the two largest reservations in the State.

SD EHDI will continue to reach out to stakeholders within the Indian Health Services to expand this partnership. The SD EHDI Collaborative will also seek partnerships with stakeholders and organizations that have a successful track record working with the American Indian population. We will also be sensitive to the needs of the Indian Health Services centers regarding the availability of staff and capability to initiate interventions at their sites. It is also important to note that cultural sensitivity is of utmost importance and should be taken into consideration. Face-to-face meetings often work best, as compared to teleconference.

**Challenge 4: Involvement of providers and parents in the Advisory Board.** The SD EHDI Collaborative recognizes that many providers in SD are stretched thin with limited resources to be involved in the Advisory Board.

Resolution: It is important to be aware of the providers' limitations regarding their time and additional resources that are required to participate in the EHDI activities. Engaging health care systems' upper administration is key to the success of the program's buy-in throughout the institution. The SD EHDI Collaborative will make efforts to work around the schedules of Advisory Board members. The EHDI collaborative will provide meeting opportunities that are an effective use of the provider's time. Use of an electronic scheduling tool (Doodle Poll) will be used to establish the best meeting times. A meeting agenda will be sent out in a timely manner,

and we will also solicit feedback on ideas prior to the meetings so the time at the meeting can be used most effectively.

**Challenge 5: Collaboration with out-of-hospital birth midwives.** There is a small number of out-of-hospital birth providers in SD who attend out-of-hospital births. During prior funding cycles, out-of-hospital birth providers rarely attended meetings for the Advisory Board, CoP, and Learning Community, which made collaboration efforts difficult. It was also often challenging to establish contact with this group of providers due to their work schedule and level of communication. Additionally, some Certified Nurse Midwives (CNMs) who attend out-of-hospital birth in SD are residents of other states with little interest in SD guidelines.

Resolution: We will continue to identify strategies to effectively reach out and engage this group to ensure timely screenings of infants born out-of-hospital attended by a midwife. In 2017 a bill was signed into law to allow for the license and regulation of certified professional midwives in SD. Late in 2018 the established board began accepting applications for licensure. This has allowed for a more active and cohesive group of midwives in SD. In 2019, this group contacted the SD DOH to learn more about EHDI processes. Further efforts to strengthen the relationship with this group will be made.

**Challenge 6: Limitations of the SD DOH statewide Electronic Vital Records Screening and Surveillance (EVRSS) system prevent accurate measurement.** For future EHDI goals and objectives beyond the 1-3-6 components (late onset hearing loss, risk factors, NICU stays, etc.), EVRSS will need significant modifications to capture EHDI data children who are older and for those born outside of SD. The system was designed to accurately identify, match, collect, and report data through the recommended guidelines of the Joint Committee on Infant Hearing (JCIH) and the EHDI benchmarks known as the 1-3-6 plan. EVRSS is a web-based data system, which links all three components of the EHDI process and the metabolic laboratory and diagnostic surveillance to the birth certificate. Accurate collection of data not linked to the birth certificate will prove difficult within this system.

Resolution: Determine what changes need to be made and the feasibility of these changes.

**Challenge 7: Limited EHDI data surveillance funding limits the SD DOH from employing a data specialist.** Since June 30, 2018, the SD Department of Health no longer receives CDC EHDI funds that supported the staffing of an EHDI data surveillance specialist. The data surveillance position was a significant strategy to improve the EHDI data reporting to the Department of Health, as there are no state regulations or mandates that govern the performance and/or reporting of the EHDI process in SD. Success of the SD EHDI program is dependent on the voluntary engagement of statewide EHDI providers (hospitals, audiologists, and early intervention) within the state. EVRSS data continues to provide indicators and measurements to support and guide grant goals, in addition to programmatic strategies.

Resolution: Education of hospitals, audiologists, and early intervention to the importance of EHDI and reporting accurate and timely data to the SD DOH will be included in all training.

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

The initial evaluation design is outlined below; the design and methods will be adjusted as necessary to provide formative data and recommendations. The external evaluator will provide summarized results to the project team, partners and Advisory Board. The evaluator and team will meet each April and October to review data, make interventions, and reinforce practices that further goals. The Advisory Board will also recommend mid-course corrections.

## **Evaluation**

**Logic Model.** The logic model will be updated annually. Summative evaluation will use the model. Refer to logic model attachment.

**Data Collection Capacity | State.** The SD Department of Health (DOH) will track screening, diagnosis, and early intervention. Since June 30, 2018, SD DOH no longer receives CDC EHDI funds that supported the staffing of an EHDI data surveillance specialist. The data surveillance position was a significant strategy to improve the EHDI data reporting to the Department of Health, as there are no state regulations or mandates that govern the performance and/or reporting of the EHDI process in SD. Success of the SD EHDI program is dependent on the voluntary engagement of statewide EHDI providers (hospitals, audiologists, and early intervention) within the state. EVRSS data continues to provide indicators and measurements to support and guide grant goals, objectives in addition to programmatic strategies.

The needs assessment will explore how best to capture and analyze the data. The evaluation will assess how well the processes are implemented.

**Newborn through 3-year-old Screening Tracking.** Ensure all newborns are screened by 1 month of age. The SD DOH Office of Vital Records office, Electronic Vital Records Screening and Surveillance (EVRSS) system was established as the SD EHDI Surveillance and Information System (EHDI-IS). Implemented in 2002, EVRSS provides newborn screening (metabolic and hearing) surveillance and tracking for infants born in SD. The system was designed to accurately identify, match, collect and report data through the recommended guidelines of the Joint Committee on Infant Hearing (JCIH) and the EHDI benchmarks known as the 1-3-6 plan. EVRSS is a web-based data system, which links all three components of the EHDI process and the metabolic laboratory and diagnostic surveillance to the birth certificate.

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.

**Diagnosis Tracking.** Ensure all newborns are diagnosed by 3 months 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. Track diagnosis through ERVSS.

**EI Enrollment.** Ensure all children are enrolled in EI by 6 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. Track EI enrollment through ERVSS.

**Family Support Services.** 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. SD currently does not have a tracking system to track family support services. The tracking system will be developed during Year 1 of the grant by the external evaluator.

**DHH Adult-to-Family Support Services.** Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age. The tracking system



will be developed during Year 1 of the grant. The tracking system will be developed during Year 1 of the grant by the external evaluator.

**Diversity and Inclusion Analysis.** Analyze the EHDI system to ensure the program activities are inclusive and address the needs of the populations it services, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, and socio-economic status.

**Parent Telephone Interviews.** Parent interviews will be conducted each January during the grant period. The purpose of the parent telephone interviews will be to solicit feedback on how the healthcare system, family supports, and SD EHDI136 app meet parent and children's needs. Findings will be used to guide the implementation of strategies to increase acceptance and successful implementation of the teleaudiology program, as well as integration and coordination of services for children who are identified to be deaf or hard of hearing. Parents interested in participating in the parent telephone interviews are identified by their healthcare providers and recruited from various hearing screening or audiology clinics and programs throughout the central and western parts of the state of SD with the focus on rural areas where services are limited and teleaudiology is expected to fill the gap in services. IRB ethical approval will be obtained from USD.

**EHDI136.com Usage.** The web-based application is intended to help parents track progress through the steps of the 1-3-6 step guidelines and to engage parents in the Early Hearing Detection and Intervention (EHDI) process. Aggregate de-identified data is collected via Google Analytics to evaluate the utility and usage of the website in an aggregate format which is Health Information Portability and Accountability Act of 1996 (HIPPA) compliant and which do not include any protected patient information and/or identifiers.

**Provider Education.** Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program. SD currently does not have a tracking system to track family support services. The program director will track the provider education.

**Provider Surveys and Follow-up Interviews.** Survey audience will include family practice physicians, nurse practitioners, audiology, physician assistants, nurses, social work, case managers and care coordinators, all who play an important role in coordinating the care of children who go through the EHDI process and children who are at risk for being deaf or hard of hearing. The survey will include questions but will not be limited to the following:

- 1-3-6 compliance
- Data collection and sharing within health care teams
- EHDI Toolkit
- Teleaudiology
- Provider training
- Referral process and follow-up

**Referral Process Mapping.** Map the referral processes between providers and validate with providers and parents. Conduct problem-solving meetings to provide interventions in process gaps and issues.

**Telehealth Capacity.** Teleaudiology usage and no shows will be tracked. Parents and patients will be requested to submit a short survey after each appointment to assess referral process, technology, and satisfaction.

**Website Views / Hits.** Google Analytics will analyze website views.

**Support Service Agencies Surveys and Interviews.** An annual survey and follow-up interviews will assess the status of coordination across early childhood programs with the goal to develop a plan to improve coordination and care services. Questions will include but not be limited to formal communication vehicles, training, referrals, and data sharing.

**Sustainability.** A review of the program budget, risks, barriers, and policies will be performed to develop sustainability plans post-HRSA award period.

**Data Collection**

The proposed approach to collecting primary and secondary data is outlined below.

<u>Study Population</u>	<u>Source</u>	<u>Instrument</u>	<u>Timeframe</u>
SD Children (Newborn – 3-years-old)	Medical birthing facilities, midwives, audiologists, and other providers	<ul style="list-style-type: none"> <li>▪ Hearing screening tracking</li> </ul>	Ongoing
SD Children (Newborn – 3-years-old) who screen positively for hearing loss	Diagnosis – Audiologists  Early Intervention – SD Dept of Education	<ul style="list-style-type: none"> <li>▪ Diagnosis tracking</li> <li>▪ Early Intervention tracking</li> </ul>	Ongoing
SD Parents and Guardians of Children diagnosed with DHH	Parents and Guardians of DHH children who opt into SD EHDI activities and consent to interviews and surveys	<ul style="list-style-type: none"> <li>▪ Family Support Tracking</li> <li>▪ DHH Adult-to-Family Support Services</li> <li>▪ Diversity and Inclusion Analysis</li> <li>▪ Parent Telephone Interviews</li> </ul>	Ongoing Interviews – January annually
Providers	Targeted providers will include birthing center screeners, home birth midwives, family medicine and pediatric providers, pediatric audiologists, ENTs, and early childhood providers	<ul style="list-style-type: none"> <li>▪ Provider Education Tracking</li> <li>▪ Provider Surveys and Follow-up Interviews</li> </ul>	Ongoing  Survey – January annually

Support Service

Agencies serving Families of EHDI children (newborn – 3 years old)

Contact list updated by Program Manager

- Support Service Agency Survey and Follow-up Interviews

January annually

**Evaluator Qualifications**

Sage Project Consultants, LLC (Sage) specializes in program and project evaluation services. Established in 2010, Sage is based out of Sioux Falls, SD. Their clientele varies from institutions of higher education, city and state governments including public health, community nonprofits and large for-profit ventures, primarily across the Midwest.

Sharon Chontos, President, will lead the qualitative and quantitative data collection, analysis, and report compilation for this project. Chontos has a B.S. in Chemical Engineering from South Dakota School of Mines and Technology and maintains an active membership with the American Evaluators Association. She has 15 years of corporate experience in the petroleum and renewable energy fields including holding the position of Research Operations Director for a leading ethanol firm. She has over 16 years of evaluation, grant management and consulting experience with non-profit and for-profit organizations, including institutions of higher education, public health departments, and health coalitions. Chontos is the lead external evaluator for the USD – NRT Neuroscience and Nanotechnology Network. Chontos is the lead external evaluator for the SD NIH INBRE program, collaborating with 7 participating universities, 60 undergraduate fellows, and 25 faculty members. She has developed and led evaluations for integrated hospital system initiatives, state and regional public health departments, and universities in the Midwest states. Chontos is also an active member of the American Evaluation Association and a panel reviewer for the NSF SBIR programs weighing in on commercial potential and project evaluation.

**Organizational Information**

**University of South Dakota (USD)**

The University of South Dakota (USD) has been accredited by the Higher Learning Commission of the North Central Association of Colleges and Schools since 1913. USD is composed of the Colleges of Arts and Sciences and Fine Arts; the Schools of Business and Education, Graduate Studies, Medicine and Health Sciences, and Law; and Statewide Educational Services. Medicine and Health Sciences are housed under the Division of Health Affairs, which includes the Sanford School of Medicine, the Division of Basic Biomedical Sciences, the Center for Disabilities, and the School of Health Sciences. The School of Health Sciences (SHS) at USD is the region’s comprehensive school of health and human services, preparing students for interprofessional, collaborative practice that meets the workforce needs of the region and innovatively moves health and human services forward. In addition to the SHS, there is capacity of other USD contributors, such as Communications Disorders, School of Education, and Head Start. Years of conducting developmental clinics around the State (including audiology assessments) through the LEND program of the Center for Disabilities demonstrates USD capacity and commitment to newborn hearing screenings and early interventions. The SHS houses the Center for the Prevention of Child Maltreatment (CPCM), which provides statewide services and resources to recognize, respond to, and eliminate child maltreatment.

Of USD’s five strategic themes, two of the themes include expanding interdisciplinary research, scholarship, and creative work and committing to a systematic, intentional, comprehensive, and

holistic approach to diversity and inclusive excellence. USD has the infrastructure to support private, state, and federally funded projects. University libraries offer technical and research support, and USD's Technology Services works with faculty to ensure the success of grant proposal projects. USD provides students, staff, and faculty with opportunities to be involved in community service, community engagement, and service-learning projects that address rural and native health disparities. In 2018 – 2019, the school supported over 25 faculty and student through service and community projects totaling over 2.5 million dollars aimed at addressing pressing health issues specific to rural and vulnerable populations. Projects addressed various health issues, including addiction, health screening, immunization clinics, advance care planning, obesity, and autism.

Funding applications submitted by USD are supported by the USD Office of Research and Sponsored Programs (ORSP), which includes a budget analyst and an accountant. These staff members are knowledgeable about grants and funding, and they maintain responsibility for financial management. The Office of Research and Sponsored Programs provides support to ensure funding agencies' goals are met.

Additionally, USD has strong, secure data systems housing large, encrypted databases. USD has faculty experts in biostatistics, epidemiology, bioinformatics, and research methods. Also, USD collaborators at the Great Plains Tribal Chairmen's Health Board are always willing to partner and have strong connections with Early Start programs in American Indian communities. The grant team at USD has developed strong collaborative relationships with the South Dakota of Health Maternal Child Division and the Office of Rural Health. The projects were completed on time and achieved their expected outcomes.

A number of information technology-based projects are supported by USD Information Technology Services (ITS). This includes project that have resulted from prior HRSA grants like the teleaudiology network infrastructure and development of a Project ECHO program and hub. USD ITS assists in ensuring updates occur as needed and have the capacity to assist with the expansion of these projects.

### **USD Center for Disabilities, LEND, and Early Intervention**

The Center for Disabilities at the University of South Dakota Sanford School of Medicine is the State's federally designated University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD). The Center for Disabilities is one of 67 UCEDD's in the United States. The mission of the Center for Disabilities is to improve the lives of individuals with disabilities and their families with a vision that all people can achieve independence, self-determination, productivity, and community inclusion. The Center engages in preservice training, community education, clinical services, research, information dissemination, and policy and advocacy related initiatives. Working to meet the needs of people with disabilities and their families in SD and the region since 1971, the Center focuses on promoting best practices, building capacity, and impacting systems change in collaboration with community partners. The Center provides leadership in the areas of autism and related neurodevelopmental disorders, deaf-blindness, employment, education, early intervention, fetal alcohol spectrum disorders, health care transitions, technology, transition to adulthood, among others. Currently, the Center administers approximately 20 grants and contracts totaling more than 3.5 million dollars.

The Center for Disabilities administers the South Dakota Leadership Education in Neurodevelopmental and Related Disabilities (SD LEND) Program funded by the Health Resources and Service Administration - (HRSA) Maternal and Child Health Bureau (MCHB). The SD LEND Program provides long-term graduate level interdisciplinary training as well as

interdisciplinary services and care. The purpose of the SD LEND training program is to improve the health of infants, children, and adolescents with disabilities. This is accomplished by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields and by ensuring high levels of interdisciplinary clinical competence. SD LEND prepares its pre-service trainees to assume clinical and leadership roles dedicated to meeting the needs of children with neurodevelopmental and related disabilities in all settings where care may be provided (home, ambulatory care settings, managed care and office settings, community based, and hospital health care facilities).

SD LEND has included audiology trainees in its endeavors each year since its inception in 1991 (totaling 44 audiology trainees) and has received a Pediatric Audiology Expansion grant since 2009. Since 2009, the SD LEND Pediatric Audiology trainee program has provided advanced clinical training, research opportunities, didactic experiences, and leadership development for 28 long-term audiology trainees (four per academic year). Audiology trainees receive specific knowledge and skills in the areas of interdisciplinary assessment, identification, and intervention for hearing loss/deafness and other auditory disorders in infants and children. The program has also provided education regarding the importance of pediatric audiology to hundreds of SD LEND trainees in other disciplines. A particular strength of the SD LEND Pediatric Audiology training program is its emphasis on providing interdisciplinary, family centered, and culturally competent services that focus not only on peripheral hearing loss/deafness but also on the evaluation of and intervention for other auditory disorders and difficulties, such as central auditory processing disorders. The majority of our past Pediatric Audiology trainees are now working in leadership roles and on interdisciplinary clinic teams in underserved/rural areas, and several have developed new, comprehensive pediatric audiology services and programs in their respective locations.

The Center for Disabilities also administers part of the SD's federal Early Intervention Program for Infants and Toddlers with Disabilities (Part C of the Individuals with Disabilities Education Act (IDEA) 2004, Public Law 108-446). Birth to Three is a program of the SD DOE, Office of Educational Services and Supports. The SD Birth to Three Early Intervention Program serves children from birth to 36 months with developmental delays or disabilities and their families. It is a family focused in-home system of services and supports for families to help understand their child's development and specific training to assist the family in addressing these areas of delay. The Center for Disabilities is contracted by the state to provide service coordination in Minnehaha, Turner, Davison, Hanson, McCook, Sanborn, Brookings, Moody, Miner, and Lake Counties in southeast SD.

Due to the growth in this area, the Birth to three staff at the Center provides service coordination to one third of SD's families participating in the Birth to three Program. The staff worked with 685 families with infants and toddlers receiving Birth to Three Early Intervention services throughout 2018 and received a perfect rating for meeting all state and federal reporting requirements. In addition, they made a total of 4,934 family contacts throughout the year and held a total of 342 initial Individualized Family Service Plan (IFSP) meetings.

The Deaf Blind Program at the Center for Disabilities, funded by the U.S. Department of Education, provides statewide services to address the needs of individuals from birth through the age of 22 with dual sensory loss to ensure that the unique needs of children who are deaf blind are met with high quality, appropriate services. The program serves approximately 30 individuals and families across the state that qualify for these services due to a combined vision and hearing loss. Services consist of technical assistance, training, and resources for both families and service providers. Increased efforts have also been made to reach out to the underserved American Indian

communities in SD. This year, all-tribal schools were included in the child find activities, which includes individual mailings to all schools, providing information about the Deaf-Blind Program, and additional state, local, and national resources.

### **South Dakota School for the Deaf**

The mission of the South Dakota School for the Deaf (SDSD) is “Partners in Educational Success.” SDSD works to provide quality educational programs for children and their families, serving 561 students across the state with varying hearing levels. SDSD supports students and families with Outreach services, Student Evaluations, Audiological screenings, and evaluations at both East River and West River clinics and throughout the state in the SDSD Mobile Lab.

SDSD has increased its caseloads dramatically in the last few years, working with families of young children in their homes and working with public school teachers. Each year there are several planned activities statewide for families, students, and teachers. Many of these activities happen in cooperation with deaf adults.

The Outreach and Audiology programs each have a Director. SDSD has 11 consultants around the state, each with a caseload of students/families. The Service Coordinator coordinates and leads the student evaluation team, website, newsletters, and assists with other tasks. Most staff have master’s degrees. Select consultants specialize in different areas, such as speech, listening, and language, student transitions, and American Sign Language.

SDSD works in a collaborative consultation model. SDSD Consultants work with a variety of different agencies across the state to meet the unique needs of their students. The SDSD Foundation is supportive of SDSD’s mission. SDSD hosts the biennial Midwest Conference on Deaf Education.

SDSD serves and supports children who are deaf or hard of hearing across the state of SD. SD is a rural state where consultants will travel many hours during a week to provide on-site support in homes and school districts. Tele-visits are used to connect with families and educators in rural areas.

### **South Dakota Department of Health**

The South Dakota Department of Health’s (DOH) vision is Healthy People, Healthy Communities, Healthy South Dakota. Its mission is to promote, protect and improve the health of every South Dakotan. SD DOH’s guiding principles are to serve with integrity and respect, eliminate health disparities, demonstrate leadership and accountability, focus on prevention and outcomes, leverage partnerships, and promote innovation. The SD EHDI program is located within the Department of Health, Division of Family and Community Health, Office of Child and Family Services.

The DOH public health services are delivered by DOH staff working in a network of 77 sites across the state. These offices are under the leadership of the Title V administrator. The DOH is part of a program to address the critical need for healthcare workers in the state, focused on health career information and opportunities for South Dakota students at all levels.

The DOH continues to identify potential strategies to address challenges such as the disparities within our American Indian population; successfully marketing program services to reach all eligible populations; recruiting and retaining adequately trained/prepared individuals for workforce, especially in remote counties and reservation communities; appropriately working with cultural differences and beliefs; impact of social media, both good and bad; and access to dental and mental health services. South Dakota is also seeing new geographical pockets of culturally diverse populations in areas with very limited resources. The DOH remains committed to fostering relationships with both IHS staff and statewide tribal government/tribal health to discuss DOH services on South Dakota Indian reservations. In addition, the DOH also remains committed to

providing comprehensive public health services to underserved populations and communities throughout the state, which includes over 54 Hutterite colonies as well as the refugee resettlement of the Burmese Karen populations in the Huron and Aberdeen areas. A wide array of public health services are provided to these communities which includes interpreter services, direct services, and outreach services provided by WIC, Title X Family Planning, and Nurse Home Visiting program. Furthermore, the MCH program is able to provide additional services including infant safe sleep education; health and safety information; immunizations; growth and development screenings; case management for high-risk pregnancy; postpartum care and prenatal education; and support services for families with children and youth with special health care needs.

## References

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- <sup>1</sup> South Dakota Department of Health. Hearing EHDI Results. Unpublished raw data. Retrieved from EVRSS February 19, 2019
- <sup>2</sup> South Dakota Department of Tourism. South Dakota Facts. <https://www.travelsouthdakota.com/trip-ideas/article/south-dakota-facts> Accessed October 25, 2019.
- <sup>3</sup> United States Census Bureau. <https://www.census.gov/en.html><https://www.census.gov/quickfacts/SD> Accessed October 16, 2019.
- <sup>4</sup> Native Governance Center. Need to Know: South Dakota Tribes. <https://nativegov.org/south-dakota-tribes/>. Accessed October 25, 2019.
- <sup>5</sup> South Dakota Department of Health. <https://doh.sd.gov/statistics/2017Vital/>. Accessed October 17, 2019.
- <sup>6</sup> Alker, J., Pham, O. Nation's Progress on Children's Health Coverage Reverses Course. Georgetown University Health Policy Institute Center for Children and Families. [https://ccf.georgetown.edu/wp-content/uploads/2018/11/UninsuredKids2018\\_Final\\_asof1128743pm.pdf](https://ccf.georgetown.edu/wp-content/uploads/2018/11/UninsuredKids2018_Final_asof1128743pm.pdf) November 2018. Accessed October 25, 2019.
- <sup>7</sup> Lutheran Social Services of South Dakota. Center for New Americans Fact Sheet. <https://www.lsssd.org/what-we-do/family-services/center-for-new-americans/index.html>.
- <sup>8</sup> Gambino CT, EN; Fitzwater, JT; The Foreign-Born Population From Africa: 2008-2012. US Department of Commerce, Census Bureau, 2014.
- <sup>9</sup> South Dakota Department of Health. South Dakota License Hearing Aid Dispensers and Audiologists. <https://doh.sd.gov/boards/audiology/roster.aspx>. Published October 1, 2019. Accessed October 17, 2019.
- <sup>10</sup> Springer, M., Obiozor, D., Kupersmidt, S. 2019. Immigrants and Refugees in South Dakota: A Health Needs Assessment. MNRS, Kansas City, KA, March 27-30, 2019. Poster presentation.