Project Title Early Hearing Detection and Intervention Program

NARRATIVE

INTRODUCTION

The Kansas Newborn Hearing Screening Program (SoundBeginnings-Early Hearing Detection and Intervention – SB EHDI) is an essential public health service provided by the Kansas Department of Health & Environment (KDHE). The Program provides this service to families with newborn infants in collaboration with hospitals, doctors, audiologists, and early intervention networks. Kansas began screening for the early detection of hearing loss in newborn infants in July 1999. Kansas Law (K.S.A. 65-1,157a) mandates that every child born in the state of Kansas shall be given a screening examination for the detection of hearing loss within five days of birth, unless a different time period is medically indicated. The law also ensures the establishment of: standards for screening equipment; screening protocols; standards for professional qualifications and training; and required reporting to guide the SB-EDHI program.

The purpose of the EHDI program is to ensure families with newborns, infants, and young children up to 3 years of age who are deaf or hard of hearing (DHH) receive the appropriate and timely services that including the newborn hearing screen, diagnosis, and early intervention. The goal of the program is consistent with the Early Hearing Detection and Intervention (EHDI) Act of 2017 and the 2007 Joint Committee on Infant Hearing (JCIH) Position Statement. The primary goal is to improve the quality of life with children with hearing loss and their families by reducing the number of infants who are lost to follow-up to newborn hearing screening, ensuring audiologic evaluations and referral to early intervention services to optimize language, literacy, cognitive, social, and emotional development.

Kansas EHDI provides tracking and surveillance of infants from hospital screening to the infant's primary care physician, to the audiologist, and to the agencies that provide early intervention, ensuring that infants complete the hearing screening process and receive early intervention services if diagnosed with hearing loss. An Advisory Committee and key stakeholders support Kansas EHDI in their efforts. It is important to recognize that newborn hearing screening is only one component of a comprehensive approach to the management of childhood hearing loss. The process also requires follow-up diagnostic services, counseling, intervention programs, and parental educational programs. A multidisciplinary team consisting of individuals such as audiologists, physicians, educators, speech/language pathologists, nurses, and parents must administer this comprehensive process.

Early and consistent screening, particularly for hearing loss, and enrollment in early intervention services once infants have been diagnosed with hearing loss is critical in achieving normal language development. Recent research has concluded that children born with a hearing loss who are identified and given appropriate intervention before 6 months of age demonstrated significantly better speech and reading comprehension than children identified after 6 months of age (Yoshinaga-Itano & Apuzzo, 1998; Yoshinaga-Itano et al., 1998).

The program objectives are:

1. To maintain a 98 percent or higher screening rate of the number of infants that complete the newborn screen no later than 1 month of age.

2. To achieve a minimum rate of 85 percent of the number of infants that complete a diagnostic evaluation no later than 3 months of age.

3. To achieve a minimum rate of 80 percent of the number of infants identified to be DHH that are enrolled in early intervention services no later than 6 months of age.

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

5. To increase by 10 percent from the year 1 baseline data the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.

6. To increase by 10 percent from the year 1 baseline data the number of health professionals and service providers trained on key aspects of the EHDI program.

Further focus through this funding opportunity are on efforts to address diversity and inclusion of the needs of the population it serves and strengthening the partnership stakeholders and organizations that provide expanded hearing screenings for children up to 3 years of age such as Health Start Home Visitors, Early Head Start, Parents as Teachers, Part C, Title V Children and Youth with Special Health Care Needs and Health Departments. Lastly, a focus on program sustainability with efforts to fund the EHDI program if funding continues to decrease.

NEEDS ASSESSMENT

Hearing is critical for the development of speech, language, communication skills, and learning. The earlier that hearing loss occurs in a child's life, the more serious the effect on the child's development. Similarly, the earlier the hearing loss is identified and intervention begins, the more likely it is that the delays in speech and language development will be diminished. Left undetected, mild or unilateral hearing loss can result in delayed speech and language acquisition, social-emotional or behavioral problems, and lags in academic achievement (Yoshinaga-Itano et al., 1998; Bess, 1985; Bess et al., 1988). With appropriate early intervention, children with hearing loss can be mainstreamed in regular elementary and secondary education classrooms.

Communication development and behavioral skills are influenced by a child’s ability to hear. Hearing loss can also affect a child’s social interactions, emotional development, and academic performance. Children with the earliest access to the speech signal through amplification, overall, will have the best outcomes on auditory-

based communication measures. Age at amplification is the factor that explains the largest percentage of variance for both measures of speech perception and is also a significant predictor of language and speech production. Decreased auditory sensitivity manifested early in life can adversely affect the development of language, oral communication, cognition, and educational progress. Intervention, provided in a timely manner has been shown to mitigate some of the deleterious effects of early hearing loss (Yoshinaga-Itano, Sedey, Coutler, & Mehl, 1998; Kennedy et al., 2006; Moeller, 2000). Development of mature spoken communication depends on the capacity of the auditory channel to receive and transmit information to the central nervous system early during development. Spoken communication is learned primarily through the auditory modality, therefore early-onset hearing loss will result in reduced ability to perceive and produce intelligible speech.

Kansas is a profoundly rural state, with one-third of the population living in two-thirds of its land mass. Of the 105 counties in KS, 85% (89/105) are considered rural with less than 40 persons per square mile and one-third of counties represent an enduring frontier with less than 6 persons per square mile, mostly concentrated in the western part of the state. Kansas has a shortage of pediatric audiologists who are knowledgeable in performing appropriate testing. The state has only eight pediatric audiology facilities, which are located in only three cities: Kansas City, Wichita, and Topeka. This leaves the western part of the state underserved for diagnostic audiological evaluations and is a presumed factor in infants receiving diagnosis after 3 months of age. In addition, there are gaps in services in many regions of the state and barriers to services due to lack of funding, professional expertise in deafness and hard of hearing, family support services, language barriers and transportation issues. Transportation often becomes an issue for families, reducing their ability to follow up with providers in the urban areas of the state.

In 2018, there were 38,047 Kansas live births. Kansas EHDI has accomplished and maintained the national goal of screening infants by one month of age as indicated in the Principles and Guidelines for Early Hearing Detection and Intervention from the Joint Committee on Infant Hearing (JCIH), 2007. Kansas screened 98% (37,388 of 38,047 of all newborns for hearing loss prior to birthing facility discharge during calendar year 2018. Five hundred nine infants were not screened. . Of the 509 infants not screened, 109 (21.4%) were born out of the hospital, supporting the need for ongoing and increased partnership and collaboration with the midwives and doulas in our state. Of the remaining infants not screened, 150 (29.5%) had deceased prior to screening

Of the infants screened for hearing loss, five hundred sixty infants were referred for further screening or audiologic evaluation. Of those, 87% received a diagnostic evaluation and 80%of those that received the diagnostic evaluation did so before 3 months of age. The trend from 2015 to 2018 reveals a decrease in the number of infants referred for diagnostic evaluations. Infants admitted to the Neonatal Intensive Care Unit (NICU) played a critical component to this percent. Infants admitted to the NICU for long periods do not meet the JCIH recommended guidelines.

The 2018, the Loss to Follow-Up/Loss to Documentation (LFU/LTD) rate for diagnosis for the state of Kansas is 6.65%. This rate has remained under 10% for the

past five years. Loss to Follow Up represents the percent of infants who failed the initial screen and have not received a diagnosis.

In the state of Kansas, all children with hearing loss or auditory neuropathy, congenital or acquired, are eligible for support and services from Kansas Infant-Toddler (Part C) regardless of the severity or type of hearing loss. Kansas EHDI is a primary referral source to the Part C program and initiates referral at the time the diagnosis is reported to the state. In Kansas, it is the role of the diagnosing audiologist to make the referral. The Early Intervention (EI) support and services provided are offered whether the infant has a unilateral or bilateral loss and whether or not the child has hearing aids, cochlear implants, other assistive devices or uses American Sign Language (ASL). A common barrier identified is that some children do not receive timely follow-up, delaying diagnosis, treatment and access to EI services. This greatly affects developmental outcomes for the child. (Yoshinaga-Itano, Sedey, Coutler, & Mehl, 1998; Kennedy et al., 2006; Moeller, 2000)

Kansas EHDI regulations prohibit any infant to be denied a hearing screening or diagnostic evaluation based on inability to pay or in the absence of a third party payer. Currently, the Kansas Title V Special Health Care Needs (SHCN) program, a state program based on medical and financial eligibility requirements, can provide financial support for a one-time outpatient screening and/or diagnostic evaluation. Conditions affecting hearing are medically eligible with the financial requirement of being at or under 185% of federal poverty guidelines. All authorized services include diagnosis and follow-up care with an ENT/Audiology specialist who is an approved provider for SHCN. All services must be authorized in advance and require annual follow-up evaluations as long as medically necessary.

Kansas EHDI also works with Early Head Start, Parents as Teachers, County Health Departments, WIC, Federally Qualified Health Centers and Home Visiting programs across the state providing Otoacoustic Emission (OAE) trainings and continuous audiological and hearing screening support to the birth to three population. These partnerships provide additional referral points and links to local communities and families for follow-up services.

Historically from 2016 to 2018, the prevalence of infants identified with hearing loss in the state of Kansas was 1.8 per 1,000 screened. In 2018, 66 infants were reported to Kansas EHDI as having been identified with some degree of hearing loss. Sixty-three (63%) of these children were eligible for EI services through Part C (3 were non-Kansas residents), but only 84% (53/63) of those identified with hearing loss received these services. Of those that received services, 82% did so before the recommended 6 months of age. Of those reported to Kansas EHDI as not receiving services, five families denied services (3 unilateral and 2 mild losses).

Out-of-hospital birth screenings have increased to 64% (193 in 2008 to 533 in 2018) over the last ten years. Many midwives throughout the state do not have the funding opportunities or accessibility to hearing screening equipment. The information shared recently with the midwives pertaining to the importance of the screen, “being the only screen that measures the hearing levels at which speech and language are produced” and the hearing loss simulator made a large impact on how they now perceive the importance of the screen. Providing midwives with equipment or the

funding for equipment could have a large impact on the development of the child born in a less restrictive manner than the ideal hospital setting. All infants should have equal access to the same newborn screenings. One barrier to out-of-hospital births is reaching the Amish and Mennonite families in Southeast Kansas.

Kansas EHDI has made great improvements over the last several years. Ongoing monitoring, education of professionals and consistent training will be necessary to ensure this benchmark remains at this level. By routinely monitoring the measures for comparison and continuous quality improvement, the grant project will support the development of statewide programs and systems of care that ensure that deaf or hard of hearing children are identified through newborn and infant hearing screening and receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy, and social-emotional development. Activities during the grant period will also support the expanding and strengthening efforts related to improving initiatives on increasing health professional's knowledge and engagement, improved timeliness of diagnosis, improving access to EI services and language acquisition, as well as improving family engagement, partnership, and leadership.

METHODOLOGY

The project focus is increasing professional engagement and knowledge of the EHDI system, improving access to early intervention services and language acquisition, and improving family engagement, partnership, and leadership within the EHDI system. Kansas EHDI will support the development of systems of care and/or statewide programs to ensure that children diagnosed through the universal newborn hearing screening program will receive timely diagnosis and appropriate intervention that optimizes their language, literacy, and social-emotional development.

The proposed methods to address the stated needs that will meet the described program goal, objectives, requirements and expectations are:

Strategy 1 - Lead efforts to engage all stakeholders in the state EHDI system to improve developmental outcomes for children who are DHH.

Objective 1.1 – Create a Partnership Assessment.

Partnership is defined as a structured arrangement between Kansas EHDI and other healthcare stakeholders (e.g., hospitals, audiologists, state agencies, health departments, early head start, parents as teachers, medical providers, early childhood providers, etc.) who provide services to infants and children. The objective is to help the partnering organizations to work together more effectively to maximize the impact of identifying children with hearing loss and ensuring the appropriate services are provided to families. It is important as we work together to have open and honest dialogue identifying the strengths, gaps, challenges, and opportunities. EHDI Staff will create a Collaboration Cross Assessment of the programs. Identification of barriers and gaps will be key components of the assessment. SB EHDI will use the Wilder Collaboration Factors Inventory and the Levels of Collaboration Scale to evaluate the collaboration

partnerships. When the assessment is complete, the EHDI staff will invite the partners to come together to discuss the needs of each programs, the strengths and weaknesses and to develop a collaboration plan to resolve barriers and improve collaboration. By the end of year 2, an action plan will be placed and EHDI staff will monitor the progress.

Objective 1.2 – Improve Partnerships

The assessment will map and identify each EHDI Stakeholder's program's screenings, services provided, referrals, and ability to share data and or annual screenings. From the results, EHDI staff will determine which programs need hearing screening trainings, resources for parents and families, and data sharing agreements. EHDI Staff will assess the partnerships on an annual basis, identify improvements area, family support, and continue to reach out to the partners to offer areas of increased collaboration.

Objective 1.3 – Address diversity and Inclusion of Midwives

EHDI will increase the inclusion of midwives across Kansas. EHDI will analyze the hearing screening data and determine areas throughout Kansas with low Out of Hospital (OHB) screen rates. The SB-EHDI information system (EHDI-IS) has the ability to generate needed reports. EHDI staff will reach out to the midwives in the targeted areas to discuss interest in obtaining funding to purchase OAE hearing screening equipment. EHDI will work with the Office of Vital Statistics to obtain an updated list of midwives and their contact information. An interested midwife with low screen rates will be chosen to receive the equipment. EHDI staff will provide training and support to the midwives regarding hearing screening, education on the importance of screening, the effects of an undiagnosed hearing loss.

EHDI will create and maintain a midwife repository within the EHDI-IS. This will allow in depth tracking and surveillance of the out-of-hospital births and hearing screenings. Out-of-hospital screen rates will be monitored quarterly through the EHDI-IS system. OHB Screen rates will be tracked and reported on the annual EHDI report.

Keeping the midwives informed of what is happening in the EDHI world is important and provides inclusion. A midwife list-serve will be created and pertinent information will be shared with midwives to keep them up to date on the EHDI world, new initiatives, and activities within their areas. It will serve as an avenue to share newly created resources, screening forms, or other new materials.

Objective 1.4 - Expand Infrastructure for collection of data up to 3 years of age

Early Head Start, Parents as Teachers and Part C providers perform annual hearing screens in the state of Kansas. Many but not all of these screens are reported to the EHDI program. The EHDI Coordinator, an audiologist, will contact these programs as well as the health departments to offer free OAE trainings, act as their audiology consultant, and provide support and resources as needed. The newborn hearing screening regulations indicate that a provider shall report any screenings or diagnostic results to EHDI if it is a result of the failed newborn screen. However, there is no mandate for annual hearing screens to be reported to the state departments. By

the end of year 2, the EHDI Coordinator will develop a protocol as a best practice guideline to report any annual failed screenings or diagnosed hearing losses. New memorandums of agreement will be developed as needed. Part C contacts the hearing screening program with the parent's consent if a child is receiving audiology services. A cross check is then made within the EHDI-IS to ensure that the hearing loss has been reported to the state. If the results differ, the EHDI staff contacts the diagnosing audiologist to collect the evaluation report. EHDI has a great relationship with the pediatric audiologists within Kansas. Late identified hearing losses are reported to that state. The newly developed protocol will be shared with the audiologists as well to ensure timely reporting.

Objective 1.5 – EHDI Advisory Committee

The EHDI Advisory Committee meets quarterly to review, endorse, provide guidance and promote elements of the program. Membership consists of a multidisciplinary group of professionals including audiologists, speech language pathologists, deaf educators, early childhood specialists, hospital coordinators, care coordinators, early interventionists, Part C coordinator, SHCN coordinator, Newborn Metabolic program consultant, and pediatrician, executive director of the commission for the deaf and hard of hearing, and hearing parents of deaf children and deaf parents. Kansas EHDI partners with WIC, local health departments, healthy start home visitor program, Part C providers, Early Head Start, Early intervention networks, and Parents as Teachers providing Otoacoustic emission hearing screening training and support. Continued collaboration with this diverse group of partners ensures and endorses the EHDI mission, goals, and objectives.

EHDI Staff will conduct an assessment of the current members to ensure that the committee has representation from stakeholders across EHDI. EHDI staff will ensure that a minimum of 25 percent of the committee is comprised of parents of children who are DHH and adults who are DHH. If the committee does not meet the expected representation, new parent or stakeholders will be recruited.

Objective 1.6 – Improve existing EHDI website

Kansas was awarded the 2014 EHDI website of the year. By the end of year 1, EHDI staff will review the current website to verify that it is accurate and up to date, user friendly, culturally appropriate, and appropriate for families and professionals. The EDHI staff will make the appropriate updates and add Deaf Culture/Community resources and the DHH toolkit resources for professionals. EHDI staff will ask the advisory members to view the website, make suggestions, and evaluate the quality of the website. The evaluation will guide further action, resources, or information needed.

Objective 1.7 – Utilize Quality Improvement

Kansas EHDI will select two strategies to monitor and assess its program performance by the end of year 1. Each year two new strategies will be chosen. Quality Improvement (QI) will be used as an approach through small tests of change, collecting and analyzing data to inform decision-making, and monitoring the success. QI tools will be utilized to support efficient brainstorming, sequential problem solving,

planning for implementation, and data centric evaluation. Leadership at KDHE has implemented QI in all programs and activities and conducts training for program staff to effectively implement QI. Kansas EHDI will continue to embed quality improvement activities within the EHDI program consisting of systematic and continuous acts that lead to measurable for infants and children who are deaf or hard of hearing. All data collected, analyzed is, and will be presented to the Kansas EHDI advisory committee for review and guidance.

Objective 1.8 – Sustainability

By the end of year 2, the EDHI Coordinator will continue to meet with agency leadership to address sustainability. In the event of continued reduced HRSA funding, it is proposed that the newborn hearing screening program would merge with the newborn blood and hearing screening programs as one of the primary conditions on the Recommended Uniform Screening Panel or RUSP. Revisions to state law have been proposed to include the sustainability of the hearing screening program through a newborn screening budget initiative.

Strategy 2 - Engage, educate, & train professionals/providers in the EHDI system

Objective 2.1 - Provider/Professional Presentations and Exhibits

The world is forever changing and so it is the same with the medical fields. Hearing screening has consistently improved over the past decade. In 2000, the goal was for every baby born to have a newborn hearing screen. Now almost 20 years later, babies are being screened and diagnosed in a timelier manner and now the focus is early intervention services and outcome measures. Research and data have proven that infants enrolled in EI services have a better chance of developing speech and language at the same rates as those of their hearing peers. Unfortunately, not all providers and professionals have the ability or time to be experts on everything. It is our duty as EHDI coordinators to make sure that these providers and professionals are being educated.

The EDHI Coordinator will contact four professional organizations for upcoming conference dates and locations. Abstracts and /or exhibitor registrations will be submitted to the organizations by the organization's deadline dates. The EHDI Coordinator will provide; 1) state and local EHDI information, 2) 1-3-6 recommendations, 3) need for hearing screening up to three years of age to identify, diagnose and enroll into EI those infants who later develop hearing loss, 4) share the benefits of a patient/family centered medical home and 5) the importance of communicating accurate, comprehensive, up to date evidence based information to families. EHDI will provide support to Providers and Professionals throughout the state.

Kansas EDHI provides OAE trainings for Early Head Start, Parents as Teachers, Healthy Start Home Visitors, Health Departments, Part C service providers, and hospitals. In return, the stakeholders will submit the hearing screening logs to EHDI for children up to 3 years of age. Hearing screen results are directly submitted to the EHDI program if it is in relations to a failed newborn screen. Funding for travel to provide the trainings has been reduced over the past grant cycle which in return reduces the

number of training events that EHDI can offer. Through the new grant cycle, Kansas EHDI will be able to offer more trainings. State entities will be contacted, offered training dates and the trainings will be scheduled. OAE Trainings, professional educational trainings and presentations will be tracked through the EHDI-IS. The education will continue annually throughout the grant cycle.

Objective 2.2 - Present to audiology students at state universities

The EHDI Coordinator will partner with state universities that have audiology programs annually to speak to the classes regarding the state specific EHDI system. Dates and locations will be scheduled. EHDI Coordinator will provide; 1) state and local EHDI information, 2) 1-3-6 recommendations, 3) need for hearing screening up to three years of age to identify, diagnose and enroll into EI those infants who later develop hearing loss, 4) share the benefits of a patient/family centered medical home and 5) the importance of communicating accurate, comprehensive, up to date evidence based information to families. Kansas EHDI will serve as a support system for the students and provide relevant resources. Professional educational trainings and presentations will be tracked through the EHDI-IS. The education will continue annually throughout the grant cycle.

Objective 2.3 – Present to Part C service providers

The EHDI Coordinator will present annually to the service providers that are working with DHH infants and families. Dates and locations will be scheduled. EHDI Coordinator will provide; 1) state and local EHDI information, 2) 1-3-6 recommendations, 3) need for hearing screening up to three years of age to identify, diagnose and enroll into EI those infants who later develop hearing loss, 4) share the benefits of a patient/family centered medical home and 5) the importance of communicating accurate, comprehensive, up to date evidence based information to families. EHDI will provide support to Providers and Professionals and will continue to provide the OAE new provider trainings two times a year. EHDI will share the DHH toolkit that provides support to providers working with DHH children and families. Kansas EHDI will offer to be a support system for the providers and continue to make resources available. OAE Trainings, professional educational trainings and presentations will be tracked through the EHDI-IS. The education will continue annually throughout the grant cycle.

Strategy 3 - Strengthen capacity to provide family support & engage families with Children who are DHH throughout the EHDI system

Objective 3.1 - Fund Deaf Mentor Program and PATHS Family Support Activities and Supporting You Family Support

EHDI will continue to provide 25 percent of the HRSA grant funding for family engagement and family support activities to the Kansas School of the Deaf (KSD). In the last grant cycle, KSD started the Deaf Mentor program, the “PATHS” family support activities program and the “Supporting You” family support program that provides direct family-to-family support. The Deaf Mentor program provided support to 13 families and

continues to increase the support to more families through this next grant cycle. PATHS supported eight families' activities throughout Kansas and have many more activities lined up for 2020. Supporting you will be launched by the end of 2019. Family participation in the family support activities will be tracked in the infant's record in the EHDI-IS. Participation reports will be created in the EHDI-IS system. EDHI Staff will monitor the family support programs participation rates.

Objective 3.2 – Create a family engagement tracking system in EHDI-IS

EHDI and KSD have had great success in supporting families. EHDI-IS will be enhanced to capture the activities that families are involved in. By the end of Year 1, the EHDI Coordinator will meet with the EHDI-IS developer to discuss enhancements. These enhancements will be created and implemented.

EHDI will contact the family support coordinators to discuss and create a reporting system. Protocols for reporting will be created and the collection of data will start by the beginning of Year 2. EDHI will analyze the data quarterly and will include statistics of the annual report.

Objective 3.3 – Provide family engagement resources to partners

The EHDI website has great resources. However, the family support information has not been added. EHDI will create a link on the EHDI website for the family support programs. Updated brochures will be dispersed at presentations and/or exhibits to providers and professionals. EHDI will monitor the web hits on the family support link and will monitor for increased enrollment/participation in family support activities during the second year.

Objective 3.4 – Provide Family engagement resources to families

The EHDI website has great resources. However, the family support information has not been added. EHDI will create a link on the EHDI website for the different family support programs. Updated brochures will be added in the Family Resource Guide that is funded by the EHDI program and dispersed by the diagnosing audiologists. EHDI will monitor the web hits on the family support link and will monitor for increased enrollment/participation in family support activities during the second year.

Objective 3.5 – Increase Collaboration with the Kansas Deaf Communities

Kansas has collaborated with the deaf communities simply over time and they have become supportive of the EHDI system. There is need for continued collaboration and increased support of the Deaf communities. By the end of year 1, The EDHI coordinator will contact and meet with a liaison within the deaf community to discuss ideas and ask for guidance on how to proceed, whom to contact, what organizations to involve and in what ways can we support each other. The EHDI staff will set up meetings with the deaf community members and have simple conversations, build trust, and provide resources and support. Members will be asked to join the advisory committee to provide guidance and support.

Strategy 4 - Facilitate improved care coordination and services for families and children who are deaf or hard of hearing

Objective 4.1 - Strengthen care coordination services when families do not enroll in EI

Kansas implemented care coordination in 2017 in collaboration with Special Health Care Needs program (SHCN). The Kansas SHCN care coordination project assists clients and their families in navigating the health care and other systems to achieve a holistic approach in meeting their child's health needs. EHDI collaborated with SHCN in finding and accessing the services and resources on a medical, community, and personal level to assure their child is receiving the services needed to achieve optimal health outcomes. EHDI Coordinator collaborates with SCHN and the care coordinators to assist in the understanding of the EHDI system; JCIH guidelines; local, state and national family organizations; appropriate referrals from early intervention, ophthalmology, genetic counseling; and various resources to be able to effectively and independently navigate families through these systems in the future. As partners, EHDI works with SHCN to identify needs and wants and developed an Action Plan to help achieve positive goals while providing the level of support needed. The family liaison and medical home providers use the Action Plans. When a child is identified with a hearing loss, a care coordination action plan is sent to the listed primary care physician.

Children identified with hearing loss not enrolled in early intervention services are not receiving the care coordination through the EI provider. EDHI will meet with the Part C coordinator and the Kansas School for the Deaf early interventionists to discuss why families are not enrolling and create an information sharing system to inform the EHDI stakeholders that a child is at risk for developmental speech and language delays. Together as stakeholders, we will create a protocol for contacting the families not enrolled and assist with care coordination.

Objective 4.2 – Evidence of improvement in communication, training, referrals and data sharing

Kansas EHDI will present or hold exhibits at the local family practice and pediatrician, and Part C conferences. The care coordination plan will be presented and/or displayed by the EHDI coordinator. Kansas EHDI will create a system within the EHDI-IS to track the infants identified with hearing loss who are receiving EI/Care Coordination and/or those not receiving EI/Care coordination. Parents of the infants with hearing loss not receiving the services will be contacted, educated and encouraged to participate in care coordination. The system will record the information, and any steps of care coordination for that child. The tracking system will record the care coordination partners for families. The EHDI staff will create and disperse a survey to the families regarding their experience with care coordination 9 months after diagnosis. This feedback will enable the program to make the appropriate changes or enhancements if needed.

Strategy 5 - Collaboration

Objective 5.1 - Provide fund and attend the EHDI annual conference for two staff and one family leader

EDHI will provide funding for two staff and one family leader to attend the annual EHDI conference. The staff and family leader will follow the appropriate steps in submitting a travel request to the department of human resources. The attendees will register for the conference, book their own travel and submit for reimbursement upon return of the trip. They will represent Kansas in a professional manner and participate in conference activities as appropriate. The attendees will provide a summary to the EHDI staff sharing information from the sessions attended.

Objective 5.2 – Collaboration with FL3

Kansas has not been successful in starting a Hands and Voices chapter. Yet Kansas does have a good family support base and resources. The family support programs have reached out to FL3 in the past for support and guidance and we do provide FL3 as a resource to families.

Kansas strives to continue to work to improve the family support services. In doing so, by the end of year 2, the EHDI coordinator will meet with the family support program coordinators in the state and discuss the areas of need or improvement. As a team, we will contact FL3 for guidance and support in building the family support system in Kansas. The family support stakeholders address the advisory committee for guidance on implementing any suggested activities or resources that FL3 suggests. The EDHI coordinator and the family support coordinators will monitor for areas of need and continue to contact FL3 as appropriate.

Work Plan

Kansas's EHDI goal is to provide all Kansas infants with access to an effective newborn hearing screening program which includes a physiologic screening prior to hospital discharge, outpatient referral screening before one month of age, audiologic assessment before three months of age, and amplification and early intervention before six months of age. Additionally, focus is on linkages to a medical home and family-to-family support services for all infants with a hearing loss. Finally, the Kansas EHDI program strives to ensure that all infants who do not pass the initial screening receive timely and appropriate follow-up services and OHB screening rates increase.

The goals, objectives, and activities of the work plan are focused on the following: a) engage all stakeholders in the state EHDI system to meet the program goals; b) engage, educate, and train professionals in the EHDI system; c) strengthen capacity to provide family support and engage families with children who are DHH; d) facilitate improved care coordination and services for families and children who are DHH and e) support the expanding and strengthening efforts on increasing health professionals' knowledge and engagement, improving access to EI services and language acquisition, and improving family engagement, partnership, and leadership.

Data tracking at the local and state levels will be utilized to document change and outcomes so expected improvements can be seen. Tests of change will be modified should the results not reflect the desired outcome to reduce loss to follow-up. Once the outcome reduces loss to follow-up and documentation, plans to replicate and expand successful strategies will commence. The work plan will be used as the framework for prioritizing the activities to meet the goals and objectives set forth in the Methodology section.

The project staffing will be comprised of the Kansas EHDI Coordinator/Audiologist, Program Consultants, and Senior Administrative Specialist. External partners include Sound START Coordinator, Kansas School for the Deaf, Part C Coordinator, Special Health Care Needs Coordinator, local early intervention providers, audiologists, Kansas Commission of the Deaf and Hard of Hearing executive director, NCHAM, and Chapter Champion. Key responsibilities will be to provide technical assistance to the state's newborn hearing systems and to assure interagency collaboration. Technical assistance will be provided in the areas of timely audiologic assessment; early intervention referrals; increasing professionals engagement and knowledge of the EHDI system; improving access to early intervention services and language acquisition; and improving family engagement, partnership, and leadership with in the EHDI systems. KANSAS EHDI will support the development of systems of care and/or statewide programs to ensure that the children diagnosed through the universal newborn hearing screening program will receive timely diagnosis and appropriate intervention that optimizes their language, literacy, and social-emotional development. Assistance will be provided through individual on-site visits, local and statewide conferences, workshops, telephone calls, online correspondence, and necessary trainings.

Technical assistance will be documented in the EHDI-IS for each screening, assessment, early intervention provider, or family record. Technical assistance efforts will be documented and maintained for all interagency collaborations.

Timeliness of audiological diagnostic evaluations, early intervention referrals and enrollment of services will be tracked in the Kansas EHDI-IS AURIS database. Infant Toddler Services (ITS) database system will allow Kansas EHDI the same data extraction capabilities as the early intervention networks.

RESOLUTION OF CHALLENGES

There are several challenges related to operating the Kansas EHDI program within the state of Kansas and implementing changes to the current system. First, the rural landscape of the state presents barriers to accessing hearing specialists and screening mechanisms. There are 105 counties in Kansas with representation of rural, frontier, and urban areas with a broad socioeconomic representation. There are 62 birthing facilities across the state with ranges in annual births from fewer than ten to thousands. Many parents have difficulty with transportation back to the hospital if they live hours away. Kansas EHDI provides training for Local Health Departments, Early Intervention Networks, Early Head Start, and Parents as Teacher programs. These stakeholders will go out to the home and obtain screening results on children that have

be identified as LFU/LTD due to parents' difficulty with transportation and limited access to outpatient screeners.

Second, although there is a state mandate for hearing screenings, very few midwives have the appropriate equipment to screen for hearing and have to refer the family to either another midwife who does have the equipment or a facility close to where the family resides. Over the years, many families have indicated that they have no concerns about their babies hearing, would know if their baby had hearing loss or follow-up to complete hearing screen is viewed as not important. Midwives need educated on the importance of the hearing screen, given better access to the equipment and the supported by the bureau of family health. Giving midwives access to equipment means more babies will be screened and better support to families.

Third, a lack of reporting of follow-up screens and audiological evaluations has remained a factor in Kansas' LFU/LTD despite the regulations to report diagnostic and screen results within 7 days. Actions taken to resolve this challenge have involved providing reports to birthing facilities and audiologists, issuing negligence letters to audiologists and administrators, ongoing trainings through hospital site visits and presentations to screen, and discussions of ways to improve performance, access to audiologist's knowledge about hearing screening and hearing screening equipment.

Fourth, children with unilateral or mild hearing losses often are not receiving early intervention services through the Part C. Kansas EHDI developed unilateral and mild informational sheets including reasons why early intervention is important to children with these types of loss. The informational sheets were provided to the audiologists to discuss with the families when a child was diagnosed. Part C early intervention programs differ throughout the state from county to county regarding policies and protocols. Kansas EHDI created a script for programs when first contacting families regarding enrolling in services for their child who is deaf or hard of hearing. The script and checklist were tools created to be used during the initial EI call to parents ensuring consistency and accuracy in the information shared with the parents. Kansas EHDI will educate the Part C providers on the importance of EI with unilateral and mild losses.

Fifth, Kansas EHDI has had minimum support from the Deaf communities in Kansas. Over the past year, Kansas EHDI has made great attempts to involve this community. Presentations, involvement and support of deaf mentoring program, family engagement, and taking the time to speak with individuals and show interest in learning more about their culture has started to break barriers. Through the grant, Kansas EHDI will continue to improve the collaboration, gain trust and support the deaf community to increase partnership.

It is anticipated that attempts to resolve these various challenges will lead to the reduction of Kansas' overall LFU/LTD rate, increased EI enrollment rates, and public understandings of the EHDI system. There will be a continuous focus on maintaining the national goals for EHDI. SB-EDHI will also work to align activities with other state and national plans such as Healthy Kansans 2020, KDHE Strategic Map, Governor's Road Map, and Title V MCH Action Plan. Through partnerships, the program can increase understanding of the hearing screening process, the importance of the JCIH guidelines, the importance of timely diagnosis and enrollment into EI, deaf community engagement, the benefits to all service providers and health professionals touching the

lives of our children, and improve the quality of life for children with hearing loss and their families.

Evaluation and Technical Support

Program evaluation is critical to improving effectiveness, cost efficiency, and the overall sustainability of the EHDI program. It is crucial that we enhance the capacity to strengthen relationships with other state agencies, set and implement future program priorities, provide technical assistance and to build compendium of best practices and increase family engagement. Our primary focus is to improve the quality of life for children with hearing loss and their families by increasing the number of infants who complete the hearing screening process in a timely manner and ensuring that they receive the best care and services available in Kansas.

This project will continue to collaborate with the KDHE Office of Vital Statistics in the transmission of accurate hearing screening results and demographic information into the Kansas EHDI-IS AURIS database. This system assists with ensuring timely and appropriate screening of all infants. The ongoing evaluation of grant activities will occur monthly, quarterly, and annually, depending on the activity. In order to evaluate effectiveness of these activities, process and outcome evaluations will be conducted. The process evaluation will consist of monitoring the extent to which activities are completed on time, their degree of completeness, and the quality of work performed. The outcome evaluation will determine if the activities undertaken have affected the outcomes stated in this proposal.

The project will continue to collaborate with hospitals and local audiologists to reduce refer rates by developing two-stage protocols for hospital-based screening programs. Kansas EHDI will provide assistance to encourage hospitals to strive for a refer rate at hospital discharge of 4% or less. This will allow the staff to devote time to those infants who are less likely to pass the screening and more likely to those infants that need follow-up services. The time saved in reducing the number of infants to follow can be more effectively used to assist families for timely and appropriate services.

Collaboration with partners such as Kansas Infant Toddler Services (Part C), Kansas School for the Deaf, parent representatives, tiny-k early intervention service representatives, and the University of Kansas Deaf Education Program will have an impact on the early intervention system. Meetings are ongoing in the continued implementation of a statewide system for regional Sound START Coordinators/Family Liaison to be the entry point for all families with infants who are deaf or hard of hearing. Sound START is a statewide early intervention program that serves children from birth to age three and their families. It works with tiny-k networks throughout the state to provide direct service to the child and his family. It serves as the Case Manager to coordinate services for the families. Kansas EHDI will collaborate with the University of Kansas and Kansas In-Service Training Systems to provide training for the Sound START Coordinators and early intervention providers.

The Kansas Infant Toddler Services Part C Coordinator is on the Kansas EHDI Advisory Committee and has served on the Early Intervention Task Force and Sound START Committee. Early intervention services are available statewide through 33

community based early intervention networks. Early intervention services in natural environments are standard of practice. Audiologists, speech-language pathologists, teachers of the deaf and hard of hearing, and early childhood special educators are among the service providers that are available through local Part C. This network of providers support the evaluation and development of the Individualized Family Service Plan (IFSP). This practice follows IDEA federal regulations, which support the goal of diagnosis before three months of age and the initiation of early intervention services before six months of age, with parental consent.

Kansas EHDI collaborates extensively with the state Part C program and local networks regarding early identification and intervention efforts. Hearing Screening Certification trainings have been provided in the past to early intervention providers and have received highly satisfactory evaluations. In particular, Kansas EHDI collaborates with Part C to obtain data on referrals, age of enrollment, and other early intervention outcomes. This collaboration is strong and will continue in the coming years. All Part C are required to report the same data as long as the family has provided a release of information as indicated as part of the data system. Many of the tiny-k networks have committed to obtaining releases from parents in order to share information with Kansas EHDI. This will enhance a seamless system for early intervention to infants and children with deafness or hearing loss and to ensure timely and appropriate services for families.

The Title V Special Health Care Needs (SHCN) program can access assessment services through Part C, linking with SHCN for reimbursement for the assessment. If the infant meets SHCN eligibility, family centered services provided through the child's local Part C network, are reimbursable by SHCN. Data sharing at the state level for this population enhances collaboration and family-centered care. Infants who do not pass the hearing screening are eligible for a one-time outpatient hearing screen and/or audiologic assessment through SHCN approved providers. SHCN collaborates in the data collection and analysis of the number of referrals to the SCHN care coordination from Kansas EHDI, the number of deaf or hard of hearing children that have a plan, and the resources provided. Heather Smith, Director of Special Health Services contributes to the MCH Title V Block grant application and annual report, which includes reporting aggregate data for Kansas EHDI. Ms. Smith is on the SoundBeginnings Advisory Committee and is committed to ensuring hearing screening in Kansas is an effective and sustainable public health initiative.

The Newborn Metabolic/Genetic Screening Program follow-up practices and protocols have been adapted by Kansas EHDI. The collaborative database link with the Office of Vital Statistics have been implemented for Kansas EHDI including linking infants with death certificates prior to hearing screening follow-up at the state level. Kansas EHDI and Newborn Screening continue to collaborate on ways to improve linking the medical home and follow-up services. The metabolic screening and hearing screening programs share the existing Kansas EHDI AURIS.

The Kansas Chapter of the American Academy of Pediatrics (KAAP) provides ongoing support to Kansas EHDI with Greta McFarland, M.D., serving as Chapter Champion and a member on the Advisory Committee. Kansas EHDI has been pleased with the collaboration from this KAAP Chapter Champion. Evaluation and technical assistance is supported through this partnership and KAAP provides valuable state and

national information and supports collaboration with pediatricians and family practice physicians in the state.

Kansas Commission for the Deaf and Hard of Hearing (KCDHH), a statewide advocacy group, will continue to function in an advisory capacity for Kansas EHDI. The KCDHH Executive Director serves on the Kansas EHDI Advisory Committee. KCDHH quarterly board meetings provide opportunities to share updates about the Kansas EHDI program activities. Currently, the KCDHH Executive Board, which the Kansas EHDI Audiology Coordinator serves on, is continuing their support of activities with Kansas EHDI and family support initiatives.

The Kansas State Department of Education (KSDE) is represented on the Kansas EHDI Advisory Committee, and several educational audiologists, teachers of the deaf and hard of hearing, and school speech-language pathologists have been involved in the Kansas EHDI initiatives. KSDE is collaborating with Kansas EHDI on the Sound START Coordinators statewide system and on deaf education issues.

Part C has collaborated with Medicaid to use a special provider billing number for local networks, allowing them to bill for early intervention services for Medicaid-eligible infants and toddlers. Audiologic assessment, assistive devices, and speech language pathology are examples of services included in this arrangement.

KanCare, the Kansas Medicaid program, and the Kansas Children's Health Insurance Program (CHIP) are administered by the Division of Health Care Finance within the Kansas Department of Health and Environment. Kansas EHDI has access to view demographic information through the Medicaid Management Information System. The access is crucial in obtaining current information when infants are lost to follow-up, moved, changed primary care physicians or unable to contact.

Kansas EHDI collaborates with other credentialed professionals that serve as members of the Advisory Committee and provide valuable consultation to the program and project. Susie Ternes, Au.D. CCC-A, is a Pediatric Audiologist at Ascension Via Christi Rehabilitation Center in Wichita, KS. She has been active in state issues related to pediatric audiology and works with children and families. She is the executive director of the Kansas Speech Language Hearing Association and is a member of the legislature task force. Erin Schuweiler, M.S., is a birth to three coordinator at the Kansas School for the Deaf. She specializes in early intervention services for DHH children 0-3 years of age. She provides services throughout the states. Her expertise as a service provider and her knowledge of the many and varied intervention strategies is well known statewide. Ms. Schuweiler chairs the Sound START program has been instrumental in planning early intervention trainings with Kansas EHDI throughout the state. This project will collaborate and maintain relationships with state professional organizations including the Kansas Hospital Association (KHA) and Kansas Speech-Language-Hearing Association (KSHA) to provide education and information to meet the needs of their membership. The professional organizations routinely conduct training needs assessments of their memberships and are experienced at providing effective training to meet their needs. These organizations also impact the screening, assessment and early intervention programs.

Organizational Information

SoundBeginnings Newborn Hearing Screening/Early Hearing Detection and Intervention Program is committed to the national 1•3•6 guidelines supporting families in the early detection, diagnosis and timely intervention of hearing loss of infants and children in Kansas.

The project will function within the Kansas Department of Health and Environment (KDHE), Division of Public Health, Bureau of Family Health (BFH). The Bureau is directed by Rachel Sisson, MS, and includes the following sections and programs:

- Special Health Services (SHS), including Title V Special Health Care Needs, Newborn Metabolic/Genetic Screening, Newborn Hearing Screening, Infant and Toddler Services ((Part C), and Birth Defects. The Director of Special Health Services is Heather Smith, MPH.
- Children and Families, including Title V Maternal and Child Health and affiliated programming such as Teen Pregnancy Targeted Case Management and Pregnancy Maintenance Initiative, Title X Family Planning, , Home Visiting, and Healthy Start. The Director of Children and Families is Kelli Mark.
- Nutrition and WIC Services, including the federally funded Women's, Infants, and Children nutritional support program and state breastfeeding education and support. The Director of Nutrition and WIC Services is David Thomason.
- Child Care Licensing, including the oversight and licensure of child care facilities to ensure the safety of children in care outside of the home. The Director of Child Care Licensing is Lorrena Steelman.
- Policy and Administration, which includes the oversight of Bureau of Family Health statutes, regulations, and policies. The Director of the Policy and Administration is Mary Murphy.

Within the Special Health Services Section, Kansas-EHDI is under the direction of Elizabeth Schardine, M.A., Audiologist. Elizabeth supervises the Program Consultants and the Senior Administrative Specialist. All of the above programs link with Kansas EHDI in some capacity. Current Bureau of Family Health (BFH) partners include the Maternal and Infant/Perinatal Services, Healthy Start Home Visitor Services, WIC, and Infant Toddler Services. Recent discussions have allowed opportunities to increase the collaboration between the Kansas EHDI program and the Child Care Licensure and CPA and Residential Facilities sections to support education and training initiatives for these providers. Additionally, within the KDHE Bureau of Epidemiology and Public Informatics, under the direction of Charlie Hunt, State Epidemiologist Director, Kansas EHDI works with the Office of Vital Statistics to gather data and link birthing and screening records.

See Attachment 5 Project Organizational Chart

Elizabeth Schardine, M.A., is the Audiologist/Coordinator of Kansas EHDI and Project Director. She is a member of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA) and Kansas Speech-Language-

Hearing Association (KSHA). Ms. Schardine has worked with NCHAM on the Early Hearing Head Start Project. She is a NCHAM Regional VII support member for Nebraska, Missouri, and Iowa. Ms. Schardine utilizes the technical assistance offered by NCHAM and obtains Kansas participation and Family Support initiatives. Ms. Schardine provides statewide training for hospital screeners and continues to provide training to birthing facility's newborn hearing screening programs annually with the assistance of the Program Consultant. Ms. Schardine developed the Part C Hearing Screening Guidelines and provides hearing screening trainings to the early intervention network screeners, Early Head Start and Parents as Teachers programs.

Mrs. Schardine represents KDHE on the Kansas Commission for the Deaf and Hard of Hearing (KCDHH). KCDHH, an advocacy group for services and programs for Kansans who are deaf and hard of hearing, was instrumental in coordinating grass roots support for the Kansas Newborn Infant Hearing Screening Act. KCDHH serves in an advisory capacity for Kansas EHDI. Ms. Schardine also represents Kansas EHDI on the Kansas Deaf Blind Consortium. Ms. Schardine was named the 2013 Kansas Audiologist of the Year and was the Kansas state awardee for outstanding clinical achievement by the American Speech Hearing Association in 2014.

Kansas' Newborn Screening program (NBS) for metabolic/genetic disorders requires a comprehensive approach of all components of the program (screening; follow-up through diagnosis). Aggregate data from this program are included in the Title V MCH Services Block Grant Annual Report. There are similarities in program implementation between NBS and KANSAS EHDI. Continued collaboration to consider future integration of systems is ongoing.

Crystal Bermudez, Program Consultant II for the SoundBeginnings EHDI Program, oversees the data entry and tracking of all newborns and data management system under the supervision of Ms. Schardine. Responsibilities include data management and follow-up of hearing screening, audiologic/medical assessment, and early intervention follow-up data as well as follow-up with the medical home, family, and service providers. The Program Consultant II provides all reports for local, state and national reporting with the assistance of the Program Coordinator. Lisa Elliott, Program Consultant I oversees the data collection and assists the Program Coordinator with follow-up of hearing screening, audiologic/medical assessment, and early intervention follow-up data; follow-up with the medical home, family and service providers. Lisa Elliott, Program Coordinator I, is under the supervision of Ms. Schardine. Leah Sawyer, Senior Administrative Specialist provides data entry on all results that are not obtained from the birth certificate system and other information related to follow-up. Ms. Sawyer also provides all administrative support to the Kansas EHDI program and the Kansas Infant Toddler Hearing Aid Bank.

The Program Coordinator I and Program Coordinator II will also be in direct proximity to other BFH Staff who are in advisory capacities to Kansas EHDI, including: Ms. Rachel Sisson, Bureau Director, BFH; Heather Smith, SHS Director; and Ms. Christina Ray, Fiscal Analyst, BFH.

Organization Experience, Capacity and Available Resources

Kansas EHDI participated in the Maternal and Child Health Bureau grant at the Marion Downs National Center for Infant Hearing (MDNC). Through this grant, the infrastructure for an effective universal newborn hearing screening system was clearly delineated and individualized technical assistance was provided which guided Kansas in the many aspects of program implementation. The MDNC guidance emphasized a comprehensive approach to implementing a newborn hearing screening program. From this guidance an Advisory Committee and Task Forces for Newborn Hearing Screening, Audiologic and Medical Assessment/Amplification, and Early Intervention Task Forces were formed. These Infant Hearing Task Forces developed guidelines for each area, a Family Resource guide, and printed materials for hospitals on the Kansas EHDI program. The Sound START Committee, which continues to develop the Sound START program and is active in providing guidance for early intervention issues in training and service delivery.

Kansas EHDI has the capability to collect and report individual level data from multiple sources. Hospitals provide individual data to the birth certificate system, which is under the direction of the Bureau of Epidemiology and Public Health Informatics. This data is exported into a file and then imported into the Kansas EHDI-IS AURIS database. Any individual data that requires an additional screening post discharge or that was inadvertently not entered into the birth certificate system, will be provided to Kansas EHDI from the hospitals and Audiologists. Physicians report results for rescreens that they have received from Audiologists or hospitals as part of a results notification form SoundBeginnings sends on their patients. Enhancements have been made to the database that allows birthing hospital newborn hearing screening coordinators and audiologists access to enter screen and diagnostic results.

Additionally, Part C will provide an essential component for data reporting by providing Kansas EHDI with information on enrollment, age of enrollment and referrals for those families that provide releases. Sound START Coordinators will be able to provide data to Kansas EHDI as a major responsibility in data management and reporting outcomes to appropriate statewide programs. The tests of change learned from the NICHQ Learning Collaborative continue to help to reduce the lost to follow-up in Kansas.