

**UNIVERSAL NEWBORN HEARING SCREENING AND INTERVENTION
(Priority 1)
New Grant Announcement Number HRSA 05-090
CFDA #93.251**

Universal Newborn Hearing Screening and Intervention

Submitted to:

Integrated Services Branch
Division of Services for Children with Special Health Care Needs
Maternal and Child Health Bureau
Health Resources and Services Administration
U.S. Public Health Service
Department of Health and Human Services

Submitted by:

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Project Abstract

I. Project Identifier Information

1. Project Title Kansas Newborn Hearing Screening and Intervention

Project Number

Email Address ksykes@kdhe.state.ks.us

MCHB Grant Award Amount \$150,000

Total Project Funds \$150,000

Enabling Services

Population-Based Services

Infrastructure Building Services

Problem

Kansas screens more than 95 percent of newborns prior to hospital discharge. However, infants that do not pass the screening may not receive timely and appropriate follow-up services due to lack of resources within the state system, medical home and interagency coordination, and family support.

Goals and Objectives

Goal 1: Increase the number of infants that return for follow-up services after hospital discharge.

Objective 1: Reduce high refer discharge rates to 4 percent or less for individual hospitals and statewide by the project 4th quarter.

Objective 2: Identify the medical home for follow-up at discharge by the 4th quarter.

Objective 3: Increase the number of infants who receive audiologic assessment before three months of age by the 4th quarter.

Goal 2: Improve Early Intervention services for infants and their families.

Objective 1: Assist in the development and implementation of a statewide system of regional Hear Resource Coordinators specializing in deafness and hearing loss by 1st quarter.

Objective 2: Provide two Regional Hear Resource Coordinator trainings by 1st and 3rd quarter.

Objective 3: Provide two trainings for Regional Hear Resource Coordinators and Early Intervention providers by 2nd and 4th quarter.

Goal 3: Improve appropriate and timely follow-up by providing family support activities.

Objective 1: Contract a Family consultant to provide parent support to families by the 1st quarter.

Objective 2: Assist in the implementation of a family support organization and Family Conference for 15 families by the 2nd quarter.

Objective 3: Family consultant will attend the EHDI National Meeting and Beginnings annual workshop by 4th quarter.

Methodology

This project proposes to have the Program Coordinator and Data Manager provide technical assistance to the state's newborn hearing systems and to assure interagency collaboration.

Technical assistance will be provided for screening, assessment, early intervention and parent input and support. Assistance will be provided through on-site, as well as training, telephone calls, correspondence and manuals. Hospitals will receive monetary assistance to implement a

two-stage screening protocol to reduce high refer rates thus enabling follow-up for those infants who need an audiologic assessment. Regional Hear Resource Coordinators will be trained through an interagency collaboration with the Kansas School for the Deaf, University of Kansas, and the Part C Infant-Toddler Services. A single point of contact for families to be provided with intervention options and services specifically for hearing loss or deafness will provide timely and appropriate follow-up. Family Consultants will assist with implementation of a Family Support organization by receiving training from Hands and Voices organization. A Family Conference will be planned for 15 families of newly identified infants/toddlers. Staff and Family partners will attend the national EHDI meeting and Beginnings meeting for assistance in activities.

Coordination

The project will coordinate with family partners, the Sound Beginnings Advisory Committee, Special Health Services, Beginnings, NCHAM, Kansas School for the Deaf, University of Kansas, Part C Infant-Toddler Services, local hospitals, early interventions service providers and networks, as well as other public and private agencies in accomplishing the goals and objectives.

Evaluation

The evaluation of this project will be demonstrated with a variety of methods. Evaluations by participants of training and conferences will be analyzed and reported. The birth certificate system and AURIS data tracking system will report information in the areas of screening, audiologic assessment and early intervention services. Progress made in development of a family support organization will be collected, reported and analyzed annually, including activities and family support provided.

Key Words

Hearing screening, Newborn screening, Newborn infants, Early intervention, Family support

Annotation

This project will plan, demonstrate, implement and refine a sustainable infrastructure in Kansas in the following areas: screening, audiologic assessment, identifying a medical home, family input and support, early intervention, culturally competent practices, professional and public education, and evaluation. Families will benefit from this project because they will have assurance that they will receive appropriate and timely follow-up services after their baby's hearing is screened. These goals will be accomplished by a system of collaborative effort with professionals, families and consumers, including local monetary assistance to hospitals, family support organization, family conference, Regional Hear Resource Coordinators and training.

Program Narrative

Purpose of the Project

Over the past decade there has been a significant growth of newborn hearing screening programs and numerous agencies have endorsed universal newborn hearing screening (1,2). There are now 37 states with statutes requiring newborn hearing screening and 50 states that have Early Hearing Detection and Intervention (EHDI) Coordinators. Nationally, 90% of infants are being screened for hearing loss before hospital discharge with goal of a 4% refer rate (3). Kansas is screening 95% of all newborns for hearing with a refer rate of 6%. This refer rate is increasing the number of infants to track for follow-up outpatient screening or audiologic assessment by 772, for a total of 2,309 infants. National statistics indicate that only 56% of infants completed an audiologic assessment before three months of age. Kansas' experience is similar but with a larger percentage of infants, 72%, completing the hearing rescreen or audiologic assessment before three months. In addition, infants in Kansas who refer on a hearing screen prior to hospital discharge may not receive timely and appropriate follow-up due to lack of coordination with the child's medical home and other agencies. Moreover, there is a lack of statewide family support networks, community-based resources, and early intervention service providers with expertise in hearing loss and deafness.

Kansas will achieve lower refer rates by assisting hospitals to implement a two-stage protocol with the addition of Automated Auditory Brainstem Response (AABR) equipment. The AABR would be utilized if the infant refers with the Otoacoustic Emission (OAE). The refer rate for this combined approach is typically less than 2%, and utilized, would reduce the number of Kansas infants that need to have rescreening or audiologic assessment to a total of 769.

Another goal will be to improve early intervention services to families. Kansas will achieve this goal by assisting with planning, implementation, and training of eight Regional Hear Resource Coordinators to serve community referral sources, including Part C *tiny-k* infant-toddler networks. These Coordinators, experts in hearing loss and deafness, will provide one single point of contact for families and will enable them to receive the appropriate and timely services that they need for their child. In addition, Kansas will contract with a family consultant, who will provide emotional support and objective information for families who have a child who is deaf and/or hard of hearing. Further requirements of the consultant: assistance in the development and implementation of a family support organization and a family conference for 15 families with a child who has been identified recently; promotion of early identification of hearing loss; and awareness of early intervention programs, community resources, medical home availability and the benefits associated with early and appropriate services.

Needs Assessment

Kansas has been tracking individual screening data since June, 2002. In 2003, there were 40,330 live births for which 95.3% had a hearing screening prior to discharge. Of the 38,435 infants screened prior to discharge, 2,309 or 6% were referred for further screening or audiologic assessment. It is important to assist these hospitals to identify the reason for this high refer rate and to offer monetary assistance to reduce the refer rate by implementing a two-stage protocol with AABR. Efforts to obtain the infant's primary medical care provider before hospital discharge are included in the birth certificate system. However, at times, this information is obtained after the inpatient screening, thus making the information available to only some providers. Sound Beginnings sends letters to families and physicians informing them of the need

for follow-up and to ask the physician if they continue to be the child's medical care provider. Reporting of outpatient screening results and audiologic assessment has increased. Regulations that became effective on July 2, 2004 require results of any screening or assessment to be sent within 7 days. Larger hospitals receive pending lists from the Sound Beginnings Data Manager to submit information for any pending outpatient screenings, transfers or other referral information. The number of children reported to Sound Beginnings that referred for an audiologic assessment was 140 or 6% with 82 or 62% receiving assessment before three months of age. Hearing loss has been reported for 41 infants that had hearing screening prior to discharge and all were identified with a medical care provider. Families, especially in rural areas of the state, do not have easy access to an experienced and qualified pediatric audiologist. Some families must travel far distances to see one. This can delay the timely manner in which they receive an audiologic assessment. In addition, audiologists are not familiar with amplification fitting of infants less than three months of age. Sound Beginnings has had leading experts in this area come to present information on audiologic assessment and pediatric amplification. Limited funding makes it difficult for all children to receive amplification before six months of age and some children receive old technology.

The early intervention programs in Kansas have reported an increase in the number of infants seen in their communities. Data tracking of early intervention outcomes have not been implemented statewide due to the Part C database vendor has had delays and inconsistencies in the most current version of software installed at each network. A checkbox was added to the database to indicate if a release to share information with Sound Beginnings had been obtained from the family. In the interim of implementation of Regional Hear Resource Coordinators to

assist in data management reporting to Sound Beginnings, continued collaboration will be maintained with Part C and their database vendor to work through delays and to capture data elements. The exact number of families enrolled in intervention services is uncertain. The limited number of known children enrolled in early intervention services, 13, was obtained from families participating in a Family Conference. Of the 13 enrolled in early intervention services, 11 were enrolled before three months of age. The median age for enrollment was three months with a range of 1 month of age and the oldest at 14 months. The timely referral to Part C therefore cannot be ascertained without additional information on enrollment to intervention services. Early interventionists continue to request training to work with babies under 12 months of age. Families need to have access to the continuum of communication options available to them. Parents often receive information about only one method of communication. The Regional Hear Resource Coordinators will be able to provide the all options. It is also important to have the early interventionists utilize standard assessment tools in order to develop programs that are based on performance-outcomes and additional assessments may be added to the standard.

Physicians usually do not know about program options for children who are deaf and hard of hearing. Deaf and hard of hearing role models provide families with information about growing up with a hearing loss. This role model program is currently available in some geographic areas of the state but not statewide.

Newborn Hearing Screening and Part C Infant-Toddler Services are under the same agency and section of the Bureau for Children, Youth and Families which allows for collaborative efforts to

improve state systems. The Sound Beginnings Advisory Committee and Early Intervention Task Forces provide guidance to promote and enhance the entire program. Regionalization of Hear Resource Coordinators provides an opportunity to work within communities to assure community-based, culturally sensitive, and comprehensive systems.

The screening and refer rates and number of confirmed hearing loss have been disseminated to the Sound Beginnings Advisory Committee, Early Intervention providers, Kansas Speech and Hearing Language Association and other agencies.

Data Requirements

The newborn hearing screening Auris database is populated from the birth certificate system so that every newborn is accounted for regardless of place of birth in Kansas. Beginning in January, 2005 a new birth certificate system will be implemented that is web-based for the hospitals. The change in the birth certificate system should be seamless once data elements have been reassigned to convert to those elements in the Auris database. There will be additional data sets collected to provide more detailed information necessary for Healthy People 2010 requirements including race, ethnicity and mother's education. The number of live births, number of infants screened prior to hospital discharge, and number of infants with a medical home is collected from the birth certificate system. The number of infants suspected of a hearing loss with an audiologic diagnosis by 3 months of age and number of infants diagnosed with a hearing loss enrolled in a program of early intervention before 6 months of age are all measures that are obtained from audiologists in Kansas and faxed to Sound Beginnings for data entry. Hear Resource Coordinators would assist by providing early intervention data and family to

family support information to Sound Beginnings as well acting as a cross check for any reports not received from audiologists and early interventionists. As additional crosschecks or until reporting by the Hear Resource Coordinators is comprehensive and complete, collaboration is ongoing with Part C Infant-Toddler Services to obtain early intervention outcomes including age of enrollment in early intervention services and families linked to a family to family support system.

Identification of Target Population

The target population will be all newborn infants and their families born in Kansas. The State of Kansas has a diverse population that includes people from Hispanic/Latino, African American and Asian cultures. There are 105 counties with representation of rural, frontier and urban areas with a broad socioeconomic representation. The grant project will target all infants receiving a hearing screen in the hospital and subsequently focus on infants and their families who do not pass the hearing screening, who need rescreening, who need an audiologic assessment, and who need early intervention and family support services. The grant project will also target hospitals with high refer rates.

Currently 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. Refer rates higher than the national goals are barriers to follow-up and tracking for Sound Beginnings, hospital, audiologic and early intervention personnel. Regional Hear Resource Coordinators will provide the structure to further develop the family-to-family support. This project will then provide a comprehensive, community-based,

culturally sensitive system within the infant's medical home. Regional Hear Resource Coordinators and Family Consultants decrease barriers for families and provide timely services. Currently Special Health Services offers infants and their families a one-time outpatient screening and/or diagnostic evaluation, waiving program eligibility. Sound Beginnings regulation prohibits any infant to be denied a hearing screening based on inability to pay or in the absence of a third party payor. Support for Hear Resource Coordinators is currently being collaborated among the Kansas State School for the Deaf, Part C Infant-Toddler Services, University of Kansas and the Early Intervention Task Force Chair of Sound Beginnings. Sound Beginnings receives technical assistance from Families Together Inc., a parent-to-parent match program, on family conference planning and they can provide assistance in developing a support organization specific to deafness and hard of hearing. NCHAM provides technical assistance to Sound Beginnings for reducing hospital referral rates, early intervention services and family support. Kansas will participate in a physician survey to assess attitudes and knowledge of newborn hearing screening. Kansas also works with Early Head Start communities in providing continuous hearing screening to the 0-3 age populations. This is another link to communities and families for follow-up services.

Goals and Objectives

Sound Beginnings goal is that all Kansas infants will access an effective newborn hearing screening program which includes a physiologic screening prior to hospital discharge, outpatient referral screening before one month of birth, audiologic assessment before three months of age, and amplification and early intervention before six months of age and linkages to a medical home and family- to-family support for all infants with a hearing loss; ensuring that all infants

who do not pass the initial screening receive timely and appropriate follow-up services. Goals, objectives and activities are in the areas of screening, assessment, early intervention and family support. The major goals for each area are:

Goal 1: Increase the number of infants that return for follow-up services after hospital discharge.

Efforts to follow infants who do not pass the screening are spent on additional infants who have a high chance of passing a second rescreen or audiologic assessment due to the refer rate being higher than the national goal. By first lowering the refer rate to a minimum for screening prior to hospital discharge, the number of infants that return for follow-up services will have a greater opportunity to be increased with follow-up efforts utilized for a smaller number of infants.

Objective 1: Reduce high refer discharge rates to less than 4% for individual hospitals and statewide by the project 4th quarter.

Activity 1.1.1 Hospitals with refer rates greater than 4% will be provided monetary assistance to implement a two-stage screening protocol incorporating AABR equipment. Three hospitals will be selected targeting those with the highest birth rates and not currently utilizing a two-stage protocol or that are not currently providing a less than 4% refer rate with AABR.

Activity 1.1.2 Hospitals will be provided with quarterly reports of their screening rate, refer rate, and any errors in the electronic birth certificate system entry for hearing screening and reasons an infant was missed.

Activity 1.1.3 Hospitals will be provided ongoing technical assistance in the use of the equipment, reporting of screening results not captured by the birth certificate system, and providing any information to the program that will assist in identifying the medical home or transferring hospital that discharges the family to home.

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Objective 2: Identify the medical home for follow-up at discharge by the 4th quarter.

Activity 1.2.1 Technical assistance will be provided to birth registrars and hearing screeners to provide the primary medical care provider at the time of hospital discharge. This information will be included in quarterly reports sent to the newborn hearing screening coordinators.

Activity 1.2.2 The Sound Beginnings program will collaborate with the newborn metabolic/genetic screening program, WIC services, Home Visitor program, audiologists and *tiny-k* Infant-Toddler Services to obtain any medical home provider that is not identified prior to discharge.

Objective 3: Increase the number of infants who receive audiologic assessment before three months of age by the 4th quarter.

Activity 1.3.1 Sound Beginnings will disseminate information to hospitals, medical care providers and audiologists of the Regional Hearing Resource Coordinators program and staff available for single point of entry for early intervention services.

Activity 1.3.2 Hearing Resource Coordinators will provide assistance to families and providers to receive access to services in a timely manner before three months of age and document types of assistance provided in a monthly report.

Activity 1.3.3 Sound Beginnings will assist the Hearing Resource Coordinators and Audiologists to provide timely reporting of all audiologic assessments.

Goal 2: Improve Early Intervention services for infants and their families.

Objective 1: Assist in the development and implementation of a statewide system of regional Hear Resource Coordinators specializing in deafness and hearing loss by 1st quarter.

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Activity .2.1.1 Sound Beginnings will collaborate with the Kansas State School for the Deaf (KSD), Part C Infant Toddler Services, and the University of Kansas (KU) at least monthly.

Objective 2: Provide two Regional Hear Resource Coordinator trainings by 1st and 3rd quarter.

Activity 2.2.1 Collaborate with the Director of the Regional Hear Resource Coordinator, KSD, Part C, KU and local agencies in training logistics, content and needs assessment.

Activity 2.2.2 Develop and implement an evaluation to assess future needs and changes to the curriculum.

Objective 3: Provide two trainings for Regional Hear Resource Coordinators and Early Intervention providers by 2nd and 4th quarter.

Activity 2.3.1 Collaborate with the Director of the Regional Hear Resource Coordinator, KSD, Part C, KU and other local agencies in training logistics, content and needs assessment.

Activity 1.2.2 Develop and implement an evaluation to assess future needs and changes to the curriculum.

Goal 3: Improve appropriate and timely follow-up by providing family support activities.

Objective 1: Contract a Family consultant to provide parent support to families by the 1st quarter. All activities will be completed by the 1st quarter and training and information dissemination will be ongoing thereafter.

Activity 3.1.1 Complete a contract for family consultant.

Activity 3.1.2 Provide orientation and training for the family consultant.

Activity 3.1.3 Inform families, Part C, hospitals and medical care providers of children who are

suspected or confirmed with hearing loss of the availability of a family consultant.

Objective 2: Assist in the implementation of a family support organization and Family Conference for 15 families by the 2nd quarter.

Activity 3.2.1 Family Consultant will contact Hands and Voices organization to schedule training and assistance for establishing a Kansas Hands and Voices Chapter.

Activity 3.2.2 Family consultant will coordinate and chair meetings to establish the Kansas Hands and Voices Chapter.

Activity 3.2.3 Family Consultant will attend all meetings for the Family Conference and collaborate and assist with the planning, development and implementation.

Objective 3: Family Consultant will attend the EHDI National Meeting and Beginnings annual workshop by 4th quarter.

Activity 3.3.1 Family Consultant will attend EHDI National Meeting in March 2006.

Activity 3.3.2 Family Consultant will attend the Beginnings annual workshop.

Methodology

This project will have the Sound Beginnings Newborn Hearing Screening Audiologist/Coordinator, Data Manager, Hearing Resource Coordinators and Family Consultant whose 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 screening, rescreening and assessment, early intervention and parent input and support. Assistance will be provided through on-site, statewide on-site, workshops, telephone calls,

correspondence and training. Regional Hearing Resource Coordinators will be trained as well as Part C providers.

Technical assistance will be documented in the Auris Sound Beginnings' database for each screening, assessment, medical, early intervention provider or family record. Meeting minutes are maintained for all interagency collaborations. Hospital refer rates are calculated from the database which receives input from the birth certificate system and provider reports. Hospitals will complete an application for monetary support, provide original invoices and provide a report to the Sound Beginnings program on the use of these funds. Training for the Regional Hear Resource Coordinators and Early Intervention service providers will be provided through interagency collaboration with KSD, KU, and Part C. A planning committee will be established for trainings. Evaluations will be analyzed and reported for each of the trainings. Data management will be an integral part of the role of the Regional Hear Resource Coordinators providing information to the Sound Beginnings program on assessment and early intervention services. Reporting will be standardized to be utilized by all Coordinators to collect performance outcomes. Part C Infant-Toddler Services will be enhancing their database system to allow all local *tiny-k* networks the same data extraction capabilities for data to be provided to Sound Beginnings. Collaboration with Part C and their database vendor to obtain individual data for children with hearing loss on age of enrollment, family support, and intervention hearing outcomes is currently ongoing and will be completed by the end of the 1st quarter.

Family Consultant will be trained to provide unbiased emotional support and to provide parent input. Hands and Voices organization will provide training to the Family Consultant on implementing a Kansas Chapter. This will include sending two trainers to Kansas.

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A planning committee for a Family Conference will be established and the Family Consultant will be active in this committee. Staff and Family partners will attend the national EHDI meeting and Beginnings meeting for assistance in activities.

Collaboration and Coordination

This project will continue to collaborate with Vital Statistics in KDHE in populating the Auris Sound Beginnings database from the hospitals hearing screening results entered into the birth certificate system. The birth certificate system will change from an electronic system to be web-based in 2005. With the new system, Sound Beginnings will begin receiving additional data elements and will comply with race and ethnicity standards, see Appendix D. This system assists to ensure timely and appropriate screening of all infants.

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 with large birth rates. Sound Beginnings will provide assistance to encourage hospitals to strive for a refer rate at discharge of 4% or less as recommended by the American Academy of Pediatrics (AAP). This will allow the projects to devote time to those infants who are more likely to not to pass the screening and 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 Part C, Kansas School for the Deaf (KSD), Kansas State Department of Education (KSDE), and University of Kansas (KU) will have an impact on the early intervention system. Meetings are ongoing to develop and implement a statewide system of Regional Hear

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Resource Coordinators to be the entry point for all families with infants who are deaf or hard of hearing. Statewide, regions will be geographically divided into eight areas. Sound Beginnings will collaborate with the University of Kansas to provide training for the Hear Resource Coordinators and to early intervention providers. Initial discussions with these agencies propose to have the administrative lead be KSD where a deaf mentor pilot has been successfully developed.

Collaboration with parents, Families Together and Hands and Voices Organization will assist Sound Beginnings in developing a family support program specific to deafness and hearing loss. Hands and Voices will provide technical assistance and training to Sound Beginnings under a CDC Cooperative agreement. Sound Beginnings will collaborate with Beginnings and NCHAM to provide meetings where family consultants will be able to obtain information on successful family support mechanisms and tools. Family consultants will assist families to ensure that timely and appropriate services may be found for their child. The family consultants will collaborate with many of the same programs as Sound Beginnings, especially the medical home, early intervention services and the Regional Hear Coordinators. Collaboration with many public and private agencies to provide a family conference to 15 families of recently identified children who are deaf or hard of hearing is essential for family's choices, education, growth and emotional support in their journey. A successful first Journey to Sound Beginnings family conference was completed and evaluations were of high satisfaction.

Infant-Toddler Services (ITS), Part C of IDEA Coordinator is on the Sound Beginnings Advisory Committee and has served on the Early Intervention Task Force. Early intervention

services are available statewide through 36 community based early intervention networks, *tiny-k* 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 at *tiny-k* networks.

Timelines for evaluation and development of the Individualized Family Service Plan (IFSP)

follow IDEA federal regulations which support the goal of diagnosis before three months of age and, with parental consent, the initiation of early intervention services before six months of age.

Sound Beginnings collaborates extensively with Part C and *tiny-k* regarding early identification and intervention. Trainings have been provided in the past to early intervention providers and

have received highly satisfactory evaluations. In particular, collaboration with Part C to obtain data on referral, age of enrollment and other early intervention outcomes will continue to move

forward. Data software glitches have been discovered and are being resolved so that all *tiny-k* networks are required to report the same data as long as family has provided the release of

information as indicated as part of the data system. Many of the *tiny-k* networks have indicated a willingness to obtain releases from parents in order to share information with Sound Beginnings

that 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. After a workshop by

Christine Yoshinago-Itano, many early intervention providers and agencies have expressed interest in a seamless system similar to Colorado's.

Services for Children with Special Health Care Needs (CSHCN) in the BCYF can access

assessment services through ITS, linking with CSHCN for reimbursement for the assessment. If

the infant meets CSHCN eligibility, family centered services, provided through the child's *tiny-k*

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network, are reimbursable by CSHCN. Data are shared at the State level for this population. Infants who do not pass the hearing screening can access one-time outpatient hearing screen and/or audiologic assessment through CSHCN approved providers, There is no cost to the family and providers are reimbursed for their screening or assessment. Jamey Kendall, RN, director of CSHCN oversee the MCH Title V Block grant application and annual report, which includes reporting aggregate data for Sound Beginnings. Ms. Kendall is on the Sound Beginnings Advisory Committee.

The Newborn Screening Program, metabolic/genetic, follow-up, protocols, long accepted in the medical community, have been adapted by Sound Beginnings. The collaborative database link with the Office of Vital Statistics has been implemented for Sound Beginnings including linking infants with death certificates prior to hearing screening follow-up at the State level. Sound Beginnings and Newborn Screening continue to collaborate on ways to improve linking the medical home and follow-up services.

The Kansas Chapter of the American Academy of Pediatrics (KAAP) has provided ongoing support to Sound Beginnings with Dennis Cooley, M.D. serving as Chapter Champion and a member on the Advisory Committee. Sound Beginnings Project Coordinator and Pamela Nicklaus, M.D., Pediatric Otolaryngologist, provided training to KAAP members at the fall meeting. At that time, Dr. Cooley resigned as Chapter Champion due to other KAAP committee obligations including taking the lead for a newly awarded Reading Project. Sound Beginnings looks forward to continual collaboration with KAAP and the new Chapter Champion once that position has been filled by the Kansas Chapter.

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Kansas Commission for the Deaf and Hard of Hearing (KCDHH), advocacy group, will continue to function in an advisory capacity for Sound Beginnings, and its executive director is on the Sound Beginnings Advisory Committee. KCDHH quarterly board meetings allow time for updates of Sound Beginnings program activities.

Kansas State Department of Education (KSDE) has a representative on the Sound Beginnings Advisory Committee, and several educational audiologists, teachers of the deaf and hard of hearing, and school speech-language pathologists have been on the Sound Beginnings' Task Forces. KSDE is collaborating with Sound Beginnings on the Hear Resource Coordinators statewide system.

The Medicaid program and State Child Health Insurance Program, Health Wave are housed in Kansas Social Rehabilitation Services (SRS). Part C has collaborated with Medicaid to use a special provider billing number for *tiny-k* allowing them to bill for early intervention services for Medicaid eligible infants and toddlers. Audiologic Assessment, assistive devices, and speech language pathology are example of services included in this arrangement. Medicaid has a representative on the Sound Beginnings Advisory Committee.

The Leadership Education in Neurodevelopmental Disabilities (LEND) program at the Developmental Disability Center (DDC) at the Kansas University Medical Center administers the CSHCN outreach program in the tertiary care system. The LEND program also provides extensive graduate level preservice multi-disciplinary training as well as technical assistance

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throughout the state, and links with the area health education centers (AHEC's) statewide.

Sound Beginnings will continue to collaborate with the LEND program and AHEC's for distance learning opportunities and hospital personnel training coordination.

Sound Beginnings' Task Force Chairpersons have outstanding credentials and provide valuable consultation and assistance to the program and to the project. Teresa Kennalley, M.A., CCC-A, Chair of the Screening Task Force, is the Director of Audiology at Via Christi Medical Center in Wichita, KS. She has coordinated the newborn hearing screening program for the second largest birthing facility in Kansas for many years. She has again been awarded with Audiologist of the Year from the KSHA association, served as the Pediatric Audiologist for the Kansas ECHO Team in training Early Head Start providers on the use of otoacoustic equipment for continuous hearing screening. Judith Widen, PhD, CCC-A, Chair of the Assessment and Amplification Task Force is Associate Professor on the faculty of the Hearing and Speech Department of The University of Kansas Medical Center and a fellow of the American Speech-Language-Hearing Association (ASHA). Dr. Widen was one of the investigators in the NIH infant hearing screening project, specifically coordinating research addressing assessment protocols for very young infants. Dr. Widen is providing statewide training for hospital screeners and coordinates the hearing screening program for KUMC hospital. Dr. Widen and Ms. Kennalley both participated in the research study, Efficacy of a Two-Stage (OAE/AABR) Newborn Hearing Screening Protocol. Jane Schwartz is Chair of the Early Intervention Task Force. She is a Teacher for the Deaf and Hard of Hearing, working in an urban infant-toddler program in the Wichita area. Her expertise as a service provider and her knowledge of the many and varied intervention strategies is well known statewide. She has been instrumental in planning early

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intervention trainings with Sound Beginnings throughout the state. Ms. Schwartz received the National Center on Low-Incidence Disabilities (NCLID) Excellence in Education Award. Ms. Kennalley and Ms. Schwartz participated in the first Family Conference in Wichita as presenters, providing toys for children at child care, host-site for families to experience audiologic assessment and amplification ear mold choices.

This project will collaborate and maintain relationships with State professional organizations to provide education and information to meet the needs of their constituencies. The professional organizations routinely conduct training needs assessments of their memberships and are experienced at providing effective training to meet their needs. Sound Beginnings has developed and maintained relationships with the Kansas Hospital Association (KHA) and Kansas Speech-Language-Hearing Association (KSHA). These organizations also impact the screening, assessment and early intervention programs.

Administration and Organization

The project will function within the Kansas Department of Health and Environment (KDHE). KDHE has four divisions, including the Division of Health and the Center for Health and Environmental Statistics (CHES).

Located in the Division of Health is the Bureau for Children, Youth and Families (BCYF) which administers, among other programs, the following: Title V Children with Special Health Care Needs (CSHCN), Maternal and Child Health Block Grant, the Early Intervention Program for Infants and Toddlers with Disabilities (Part C) of the Individuals with Disabilities Education Act

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(IDEA), known as *tiny-k* in Kansas, Sound Beginnings, and the Newborn Screening Program (metabolic/genetic). The latter three programs are in the Children's Developmental Services Section (CDS) of the BCYF, under the direction of Carolyn Nelson. Sound Beginnings is under the direction of Kim Sykes, M.A., CCC-A and supervises the Data Manager. The Data Manager supervises the Data Registrar. CSHCN is under the direction of Jamey Kendall, RN. Other programs with links to Sound Beginnings are the Maternal and Infant/Perinatal Services, Healthy Start Home Visitor Services, which are in the Children and Families Section of the BCYF under the direction of Ileen Meyer and the WIC - Nutrition program which is in the Nutrition and WIC Services Section of the BCYF under the direction of Dave Thomason.

Organization Experience, Capacity and Available Resources

Kansas, 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 Sound Beginnings program. The Task Forces no longer actively meet. However, each of the Task Force chairs continues to provide a leadership role and serves on the Sound Beginnings Advisory Committee. The Early Intervention Task Force Chair continues to be active in

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providing guidance for early intervention issues in training and service delivery.

Sound Beginnings Advisory Committee was reorganized and began meeting in October 2001 under the direction of the Audiologist/Coordinator of Sound Beginnings. Sound Beginnings has successfully developed the working advisory committee that meets quarterly to review, endorse, provide guidance and promote elements of the state EHDI program. The members of the advisory committee represent a varied group including physician groups, audiologists, early interventionists, parents, Part C, CSHCN, family support organization, hospital association and other stakeholders, see Appendix A.

Sound Beginnings is in the Bureau for Children, Youth and Families (BCYF) which administers MCH and CSHCN, as well as a variety of other programs including the Early Intervention Program for Infants and Toddlers with Disabilities (Part C) of the Individuals with Disabilities Education Act (IDEA) and the Supplemental Nutrition Program for Women, Infants and Children (WIC).

Kim M. Sykes, M.A., CCC-A is the Audiologist/Coordinator of Sound Beginnings and Project Director. She is a member of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA), currently serves as the Secretary/Treasurer and previously served as Archivist. Ms. Sykes is also a fellow of the American Academy of Audiology, a member of the American Speech-Language-Hearing Association, American Auditory Society, Kansas Public Health Association, and the Kansas Speech-Language-Hearing Association serving as Vice President of Audiology and on the Legislative Task Force. Ms. Sykes has

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worked with NCHAM on the Hearing Head Start Project as the lead for the Kansas ECHO Team, and participated as a representative for the MCHB grantees on the EHDI National Goals Committee. Ms. Sykes utilizes the technical assistance offered by NCHAM and obtains Kansas participation on projects such as the Pediatric Audiologic Assessment Providers training and will be collaborating with NCHAM on a national physician survey. Ms. Sykes is providing statewide training for hospital screeners.

Ms. Sykes 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 Sound Beginnings. Ms. Sykes also represents Sound Beginnings on the Kansas Deaf Blind Consortium.

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 MCH Title V Block Grant Annual Report. There are similarities in program implementation between NBS and Sound Beginnings.

Megan Duncan, B.B.A., is the Data Manager for the Sound Beginnings Program and oversees the data collection, entry and tracking of all newborns and data management system under the supervision of Ms. Sykes including data management and follow-up of hearing screening, audiologic/medical assessment, and early intervention follow-up data; follow-up with the

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medical home, family and service providers. Ms. Duncan provides all reports for local, state and national reporting with the assistance of the Program Coordinator. Ms. Duncan supervises Jill Kennedy whose position is funded by Part C Infant-Toddler Services. Jill Kennedy is a deaf adult with Usher syndrome and provides data entry on all results that are not obtained from the birth certificate system excluding audiologic assessments that are entered by the Data Manager. Sound Beginnings staff is housed within the Children's Developmental Services Section, thereby having immediate proximity with the Part C Coordinator and Newborn Screening Coordinator.

The Program Coordinator and Data Manager will also be in direct proximity to other BCYF Staff who are in advisory capacities to Sound Beginnings, including: Ms. Linda Kenney, MPH, Director, BCYF; Ms. Carolyn Nelson, Children's Developmental Services Director; Ms. Jamey Kendall, RN, Director, Services for Children with Special Health Care Needs; and Ms. Shelley Russell, Fiscal Manager, BCYF.

Sound Beginnings 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 Office of Vital Statistics, and this data populates the Sound Beginnings 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 Sound Beginnings 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 Sound Beginnings sends on their patients. Part C will provide an essential component for data reporting by providing Sound Beginnings with information on enrollment, age of enrollment and referrals for

those families that provide releases. Hear Resource Coordinators will be able to provide data to Sound Beginnings as a major responsibility is data management and reporting outcomes to appropriate statewide programs.

State General Funds are allocated for the Program Coordinator, including salary and benefits, office space and furniture, communications, and some in-state travel. State funds are allocated to provide for office space: desk, chair, personal computer, and communications including phone, email and internet access for the Program Coordinator. Other equipment including copier, calculator, and shredder are supported by MCH and Part C (IDEA) funds.

References

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