

# Kansas SoundBeginnings

## Newborn Hearing Screening Program 2012 -2013 Annual Progress Report



### **REDUCING LOSS TO FOLLOW-UP AFTER FAILURE TO PASS NEWBORN HEARING SCREENING**

*NON-COMPETING CONTINUATION (NCC) PROGRESS REPORT for the reporting period April 1, 2012 - March 30, 2013*

#### **1. Project Identifier Information**

Grant Number: H61MC00031

Project Title: Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening

Organization Name: Kansas Department of Health and Environment

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#### **2. Accomplishments and Barriers**

##### **Accomplishments**

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) to families with newborn infants in collaboration with hospitals, doctors, audiologists, and early intervention networks. SB-EHDI works to ensure that all children with hearing loss are identified as early as possible and provided timely and appropriate audiological, educational, medical intervention, and family support. The EHDI program is dedicated to providing families of children identified with hearing loss unbiased support to families.

The goals and objectives of the program are consistent with the Early Hearing Detection and Intervention (EHDI) programs 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 audiological evaluations and referral to early intervention services. Approximately 42,000 infants are born in Kansas each year. Based on the national frequency of early hearing loss, it is to be expected that between 84 and 126 infants are born with some degree of hearing loss in Kansas each year. Since the enactment of the Kansas SB-EHDI program, an average of 88 infants each year are identified through this legislation.

SB-EHDI focuses on assuring and facilitating timely, comprehensive, coordinated, culturally competent care for children 0-3 years of age who are at risk for developing or have been diagnosed with hearing loss. Ultimately, our work will reduce loss to follow-up rates for infants and toddlers in Kansas and increase access to appropriate services, which will promote healthy child development. We work to establish positive communication and collaboration among key stakeholders including primary care providers (PCPs), local health departments, Women Infants and Children (WIC), families, Part C Infant Toddler tiny-k, care coordinators, specialists including audiologists and otolaryngologists (ENT), Early Head Start, Parents as Teachers, Home Visiting programs, and family support consultants. Special Health Services (SHS), Kansas's Title V Program for Special Health Care Needs (SHCN), continues to work closely with Kansas Department of Health to administer Kansas' EHDI program.

Stakeholders work together to strategically disseminate and exchange information between the medical specialty providers to ensure effective collaborating with medical homes. This grant ensures that community-based services for children with hearing loss are available, that services are offered to the families early and often easily available to access.

Auris, Welligent Database is the designated state system for hearing information on all children born in Kansas. SB-EHDI receives the hearing screening results through a web-based birth certificate system, VRVweb. This system, administered through the Kansas Office of Vital Statistics, was developed to support birthing facilities to provide on-line birth certificate transmission including newborn screening data. Daily data linkage updates export hearing screening and vital demographic data from the VRVweb and import it into SB-EHDI's AURIS newborn hearing screening data management system. Eighty-nine percent (89%) of the birthing facilities are on the VRVweb birth certificate system that account for 99% of births. All other outpatient screens and rescreens are faxed to SB-EHDI for manual entry into the database.

**Hospital Quality Assurance/Quality Improvement projects were set into place with the birthing hospitals to improve screening and loss to documentation rates for all infants born at the birthing hospital, transfers to a special care hospital, and NICU transfers.** Hospitals were provided ongoing technical assistance in the use of their hearing screening 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 transfers that occur after birth certificate entry that discharges the family to home. A hospital report card was provided to all hospitals. This included quarterly statistics regarding their screening rate, refer rate, and any errors in the VRVweb birth certificate system and for reasons an infant was missed. Technical assistance was provided to birth registrars and hearing screeners to provide the primary medical care provider at the time of hospital discharge or diagnostic evaluation. The information was included in quarterly reports sent to the newborn hearing screening coordinators. SB-EHDI collaborated with the newborn metabolic/genetic screening program, WIC services, Home Visitor program, audiologists and tiny-k Early Intervention Services to obtain any medical home provider that was not identified prior to discharge.

Letters were sent to Audiologists and other outpatient screening facilities that outlined the reporting requirements and guidelines as mandated by the state of Kansas. Webinars were development and disbursed bi-annually to UNHS hospital coordinators capturing items of interest and other pertinent resources in improving the screening and loss to follow-up rates.

**Collaboration and Education with Audiologists, Medical Home Providers, Medical Home Providers with Screening equipment, Ear Nose and Throat physicians, Midwife Associations, Birthing Classes/Lamaze, and state Speech Language Hearing Association.** SB-EHDI conducted information-sharing sessions and technical assistance to physicians, audiologists, ENT, Midwives, Birthing classes and state Speech Language Hearing Association. Information regarding UNHS laws, regulations and guidelines, medical management, taking an active role in reducing loss to follow-up, illustrating the importance of the hearing screen and reporting the results to the state EHDI program were disseminated. "Lunch and Learn" programs were presented to medical home providers. Broadcast web-based topical sessions were available and based on expressed interests and identified challenges. Evaluation instruments were developed to determine efficiency and measure systemic impact of the inclusion and training efforts. SB-EHDI facilitated coordination of services through linkages between birthing hospitals, medical home providers, ENT, and audiologists. Medical home providers were surveyed to evaluate the timeliness of reports and the effectiveness of communication from birthing hospitals and audiologists. Information regarding hearing screening was dispensed at Birthing Classes. The information sharing capacity was increased by updating the Kansas SoundBeginnings website. Kansas was honored at the 2014 EHDI Conference for having the Website of the Year.

**Improve appropriate and timely family support for families of newly identified children who are deaf or hard of hearing.** SB-EHDI contracted with parents of children with hearing loss known in Kansas as *"Family Support Consultants"* to provide parent support to families of newly identified children with loss. The availability of the Family Consultant and services they can provide will be shared with families, Part C, hospitals and medical care providers for infants who are suspected or confirmed with hearing loss. Family Support Consultants attended the annual EHDI National Meeting.

#### **Decrease the number of homebirth/out-of-hospital births Loss to Follow-Up**

Use SB-EHDI database to collect and report all out of hospital births. SB-EHDI mapped homebirths using Auris SB Web-EHDI data to identify cities of highest and lowest homebirth frequencies. Professionals and state associations related to planned homebirths were contacted. SB-EHDI staff telephoned midwives to get their input and understanding of their knowledge of the hearing screen and to offer support. It is believed that by the education and support of the midwives the rate out of hospital births increased over a years' time from 26% to 40%. SB-EHDI monitors quarterly through SB-EHDI database the number of planned homebirths and the rate of hearing screens.

#### **Collaboration, Presentations and Training**

SB-EHDI Coordinator continues to discuss the importance of collaboration, training. SB-EHDI provides the EHS, Health Departments and PAT agencies OAE trainings/refresher trainings. SB-EHDI coordinator continues to provide presentations to the state speech-language-hearing association, health departments, Part C Infant Toddler tiny K networks, hospitals, Medical Associations and on other state and national levels.

## Barriers

Kansas hospitals are screening 99% of their babies before discharge. However, Kansas continues to struggle on getting a greater number of infants diagnosed before 3 months of age and into early intervention before 6 months of age. The next grant cycle will focus on what the next steps should be to get diagnosed and into early intervention services within the national guidelines.

## 3. Goals and Objectives and Plans for Upcoming Budget Year

### Aim Statement 1

***By March 31, 2015, Kansas SB-EHDI will use quality improvement methodology to reduce the percentage of Kansas birthing facilities with refer rates higher than 10% from the baseline of 39% to 34% which in return has an impact on Kansas' LFU/LTD rates.***

#### **Objective 1.1 Review Birthing Facility QI report to identify the hospitals with higher than 10% refer rates**

Identify 5 hospitals with the highest refer rates, Provide onsite training, Monitor monthly progress of the decrease of refer rates

#### **Objective 1.2 Analyze/Track the hospital hearing screening refer rates**

Analyze the data from the hospital QI reports, Meet with stakeholders to discuss progress, Change or retire testing if no improvement of refer rates, If improvement of refer rates, implement into hospitals with the highest refer rates

### Aim Statement 2

***By March 31, 2015, Kansas SB-EHDI will use quality improvement methodology so that LFU/LTD is reduced in the percentage of Kansas newborns that do not receive rescreening and/or diagnostic audiological evaluations after failure to pass newborn hearing from a baseline of 43% to 38% by identifying partnerships and collaborating on local and state levels.***

#### **Objective 2.1 Identify ways to collaborate with Title XIX, Title V, WIC, on data sharing**

Schedule meetings with Title XIX, Title V, WIC, Create MOU, Get access to shared databases

#### **Objective 2.2 Identify 5 infants who have not received a rescreen or diagnostic evaluation by three months of age in a region with high LFU/LTD rates**

Compare demographic information in all accessible databases, Contact/Alert WIC, Home Visiting Program, MCO case managers to assist families in completing the process, Provide WIC, Home Visiting program, Case managers parental information, Provide an array of family supports statewide, (transportation, SHCN eligibility), Track/Analyze LFU rates of infants receiving rescreen or diagnostic evaluations before 3 months of age, Change or retire testing if no improvement of refer rates, If improvement of refer rates, implement for all infants in that region

**Objective 2.3 Promote Special Health Care Needs offering infants and their families a one-time outpatient screening or diagnostic evaluation at no cost**

Schedule meeting with SHCN, Collect information to share, Send out information to Audiologists, PCP, EI, families and other entities, add information on the SB-EHDI website

Aim Statement 3

***By March 31, 2015, Kansas SB-EHDI will use quality improvement methodology to decrease the LFU/LTD of infants identified with hearing loss receiving early intervention services before 6 months from baseline of 20% to 15%.***

**Objective 3.1 Identify Audiologist Protocols on referring a child newly identified with hearing loss for Part C Early Intervention Services**

Develop and distribute a means to document the referral process, Survey Audiologists to determine where the barriers or breaks might be occurring in the referral process

**Objective 3.2 Identify the KS County that has the highest number of infants identified with hearing loss with the lowest amount receiving EI services**

Identify the KS County EI Network, EI protocols for receiving referrals, Analyze to determine where the barriers or breaks might be occurring in the referral/assessment process

**Objective 3.3 Track the amount of time to complete the referral process from the initial refer to the Individual Family Service Plan (IFSP) on 5 infants identified with hearing loss within this EI network through the share Part C database**

Identify 5 infants within the network, Track the amount of time from referral to IFSP, Contact the family to provide support, Letter to families who do not choose EI

**Objective 3.4 Analyze/track the rates of infants enrolled in EI before 6 months of age**

Monitor the rates of enrollment, Meet with stakeholders to discuss progress, Change or retire cycles of testing if no improvement in LFU/LTD, If improvement of EI LFU/LTD rates, implement in another EI network

**Objective 3.5 Develop an EI packet to be distributed by the Audiologist to families**

Meet with EI and Audiologist Stakeholders to collect information for the packet, information for the families and disperse to Pediatric Audiologists

Aim Statement 4

***By March 31, 2015, Kansas SB-EHDI will use quality improvement methodology to increase the screening rate of homebirth/out-of-hospital births from the baseline of 40% to 50%.***

**Objective 4.1 Obtain names and demographic information of laypersons and certified midwives in the state of Kansas who assist in home births.**

Contact the Office of Vital Statistics to obtain names, Identify who has screening equipment

**Objective 4.2 Partner with an established Midwife in the EHDI system to host a one day (metabolic and hearing) conference in a region with the highest out of hospital birth rates**

Identify the region with the highest OHB rate, Contact a partnering midwife in that region, Work out details for the conference, Conference

**Objective 4.4 Select two midwives within the region to receive OAE equipment.**

Disperse a survey during the conference to midwives, Select the midwives from responses on survey, Schedule and provide OAE trainings, Provide resource and technical assistance as needed

**Objective 4.5 Monitor the success and the increase in OHB screen rates**

Schedule a follow-up, meeting with midwives, Monitor the screen rates of OHB, Meet with stakeholders to discuss progress, Change or retire cycles of testing if no improvement, If improvement of OHB rates, implement in conference and OAE funding in another region

## 4. Significant Changes

