

Kentucky Early Hearing Detection and Intervention

(An Application in Response to the Early Hearing Detection and Intervention Program Funding Opportunity Announcement HRSA-20-047)

INTRODUCTION

Lack of documented follow-up after failing to pass Universal Newborn Hearing Screening (UNHS) threatens the success and sustainability of Early Hearing Detection and Intervention (EHDI) programming nationwide. The Joint Committee on Infant Hearing 2007 Position Statement “endorses early detection of and intervention for infants with hearing loss.” The goal of early hearing detection and intervention is to maximize linguistic competence and literacy development for children who are deaf or hard of hearing. Without appropriate opportunities to access and learn language, these children will fall behind their hearing peers in communication, cognition, reading, and social-emotional development (Yoshinaga-Itano 2001). Such delays may result in lower educational and employment levels in adulthood.

Early identification, diagnosis and intervention are critical to language learning, school success and life-long achievement for persons born with hearing loss. As stated in the 2013 Joint Committee on Infant Hearing (JCIH) Supplement to the 2007 Position Statement, “in the United States, there is evidence that earlier identification of children who are deaf or hard of hearing, accompanied by timely and appropriate interventions, can result in language, communication, cognitive, and social-emotional skills that are consistent with children’s cognitive abilities and chronological age.”

Regardless of communication modality (e.g. American Sign Language, Cued Speech, Listening and Spoken Language, Bilingual or Bicultural), amplification and/or cultural choices made by the family, appropriate early intervention for all infants with confirmed permanent hearing loss should begin before six months of age (Joint Committee on Infant Hearing, 2007).

Fifteen key goals for achieving optimal outcomes from EHDI systems have been identified (Yoshinaga-Itano, 2011). Those which best align with this funding opportunity include:

- Report follow-up immediately to state EHDI databases
- Reduce the age of identification for children with acquired or progressive hearing loss
- Facilitate processes that increase the probability that families will follow up;
- Increase the rate of immediate referral to early intervention and ensure immediate early intervention services;
- Increase reporting of early intervention referrals of each child confirmed as deaf or hard of hearing (D/HH) to state EHDI databases;
- Ensure timely contact after referral by knowledgeable early intervention providers;
- Establish criteria for knowledge and skills of early intervention staff who first contact families of infants or children who are deaf or hard of hearing;
- Avoid providing information the family may perceive as biased, and reduce pressure on families to make immediate decisions;
- Ensure that families have peer support available as early as possible; and

- Ensure that families have an opportunity to interact with individuals and professionals who are D/HH.

In Kentucky, UNHS has been implemented since 2001 with a 96% or better screening rate prior to hospital discharge. Unfortunately, optimal timely diagnosis, early intervention enrollment and associated reporting and tracking follow-up for those that refer following the newborn hospital screening have been consistently elusive. Barriers have been identified by the Advisory Board, Audiology-EHDI staff and statewide stakeholders and include: 1) Delay in referral process from hospitals and physicians to audiologists after an infant “fails to pass” (refers) the physiologic newborn hearing screening; 2) KY EI program does not include mild bilateral or unilateral hearing loss as an Established Risk Condition (as these children do not exhibit delays at the time of referral) 3) Audiologists fail to refer babies to EI when they are aware that infants do not qualify 4) Confidentiality issues related to both Health Information Protection and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act (FERPA); and 5) Lack of accountability for primary care providers and early intervention providers for reporting follow-up after a referral resulting from UNHS.

In the last several years, Kentucky’s Early Hearing Detection and Intervention (EHDI) program within the KY Office for Children with Special Health Care Needs (OCSHCN) led the implementation of focused initiatives to reduce the loss to follow-up after infants failed to pass the newborn hearing screening. These initiatives included: 1) hired a full-time employee (FTE) follow-up coordinator and a part-time (PTE) follow-up coordinator that is a parent of a child with hearing loss; 2) scripted the message delivered to parents at the time of the hospital screening; 3) required the medical home be identified in the KY CHILD (KY Certificate of Birth, Hearing, Immunization and Lab Data) on-line submission format used by hospitals; 4) required hospitals to document follow-up appointments in KY CHILD; 5) implemented “fax back” between EHDI and physicians or diagnostic audiologists who provided follow-up testing for children that referred; 6) expanded the KY CHILD application to allow approved audiologists to search the database, enter and submit data online; 7) championed the passage of House Bill 5 which required audiologists listed on EHDI’s “Infant Audiological Assessment and Diagnostic Centers” resource list to report diagnostic follow-up to EHDI through KY CHILD electronically for KY births; 8) fiscally and programmatically supported the Kentucky Chapter of Hands and Voices to develop a Guide by Your Side Program; 9) partnered with the Kentucky Commission on the Deaf and Hard of Hearing (KCDHH) and the Family to Family Health Information Center (F2F HIC) parent consultants to develop and disseminate materials to families whose infants are diagnosed as deaf or hard of hearing; 10) implemented letters to physicians for infants that referred on their newborn hearing screen; 11) implemented letters to physicians when children were diagnosed with a permanent hearing loss.

These initiatives have resulted in significantly improved outcomes in Kentucky. The average rate of referral statewide from birthing hospitals in 2018 for infants failing to pass the physiologic newborn hearing screening prior to hospital discharge was 3.57%. The EHDI Branch of the Office for Children with Special Health Care Needs (OCSHCN) is mandated to provide tracking and surveillance for this population. Since implementation, gradual improvement in the documented, non-mandated audiology follow-up reporting to the state EHDI database has increased. In 2001, follow-up received from diagnostic audiology evaluations was 16% from

diagnostic audiologists, in 2006 it was 52%, in 2009 it was 76%, and in 2017 it was 86.7%. This gradual improvement still falls below the recommended standard of care in accordance with the JCIH 2007 position statement: the “Quality Indicator for Confirmation of Hearing Loss: Of infants who fail initial screening and any subsequent rescreening, the percentage who complete a comprehensive audiological evaluation by 3 months of age; the recommended benchmark is 90%.”

While there has been significant improvement in reaching the national benchmark of 90% for the 3 month goal, only a small improvement toward the 6 month goal of referral to and enrollment in Early Intervention following a diagnosis of permanent childhood hearing loss has been made. For infants born in 2017, approximately 26.3% of those with a diagnosed permanent hearing loss were reported as receiving timely early intervention services, well below the benchmark of 85%. Infants diagnosed with bilateral permanent sensorineural hearing loss had a slightly higher rate of enrollment by 6 months at 33.3%. It should also be noted that of the infants diagnosed with unilateral permanent hearing loss, 46.7% of them were referred to Part C by 6 months of age, but none were enrolled in services as a unilateral loss is not currently considered a qualifying diagnosis for services. The above statistics, however, likely do not reflect the true level of early intervention referral and services due to the limited information sharing currently available between EHDI and Part C.

To address the 6 month JCIH goal for the EHDI program, a Memorandum of Agreement (MOA) with Part C (First Steps) within the Department of Public Health in KY was signed in 2012 and resulted in an improved collaborative effort in referring infants and toddlers for timely diagnostic audiology services and providing aural habilitation and speech and language services to families that apply and are eligible for OCSHCN services. Also improved referral and timely linkage of infants and toddlers diagnosed as deaf or hard of hearing to warranted early intervention services was addressed by expanding the National Center for Hearing Assessment’s (NCHAM) Early Childhood Hearing Outreach (ECHO) program in KY by providing physiologic screening equipment (Otoacoustic Emissions) and training on service delivery and EHDI reporting procedures. An addendum to the existing MOA was developed addressing the acquisition of screening equipment, calibration, maintenance, purchase of consumable supplies and reporting requirements. Lastly, it was proposed that securing releases from families would also improve submission of data related to the EHDI goal of enrollment in early intervention before 6 months of age for infants who are diagnosed as deaf or hard of hearing. All of these efforts did help KY move from 29.3% in 2010 to 66.7% in 2014, however, there is much more to be accomplished.

One challenging area that encompasses all of the 1, 3, and 6 month goals is family support and engagement. In a recent survey of EHDI stakeholders, family members expressed frustration about several areas in the EHDI process, including lack of information at the time of newborn screening, primary care physicians that were not aware of protocols for follow-up testing, and providers of Early Intervention services that were not knowledgeable about the impact of hearing loss and the need for intervention even if the infant/toddler with hearing loss is apparently on target developmentally. Families made several recommendations in the survey to address ways in which support could be provided, many of which will be incorporated in the upcoming work plan.

NEEDS ASSESSMENT

General Kentucky Demographics: The state of Kentucky covers 39,486 square miles and includes a population of 4,425,092 individuals. Approximately 26 percent of Kentucky's children live in poverty (US: 20 percent),¹ and poverty rates are higher in rural communities.² The majority of Kentuckians are White (85% compared to 61% across the US), while 7% of the population is Black, 3% Hispanic, and about 2% identify as having two or more races.³ Kentucky's population distribution varies considerably across the state. For example in the Metro Louisville region, 20.6% of the population is Black.⁴

The state is geographically diverse with 79 counties designated as entirely rural. There are 144 designated primary care health professional shortage areas (HPSAs) and a total of 343 HPSAs inclusive of primary care, dental health, and mental health.⁵ Only 11 out of Kentucky's 120 counties do not have a single HPSA designation.

Health Status in Kentucky: Approximately 5.7% of Kentuckians under age 18 are reported to have a disability and disability status varies by race.⁶ In 2016, the Medicaid/CHIP Child Participation Rate was 95.6 percent in Kentucky, slightly higher than the 93.7 percent national average.⁷ Approximately 44% of births in Kentucky were financed by Medicaid in 2010, similar to the average percentage nationally.⁸

In 2017, Kentucky's birth rate was 64.5 per 1,000 women ages 15-44, slightly higher than that for the entire nation (60.3 per 1,000).⁹ From 2011-2017, Kentucky had an average of 52,459 births per year and approximately 2,622 infants refer for follow-up services through the EHDI

¹ <http://kff.org/other/state-indicator/poverty-rate-by-age/?currentTimeframe=0&selectedDistributions=children-0-18&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

² <http://kff.org/other/state-indicator/poverty-rate-by-metropolitan-status/?currentTimeframe=0&selectedRows=%7B%22nested%22:%7B%22kentucky%22:%7B%7D%7D,%22wrapups%22:%7B%22united-states%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

³ The Kaiser Family Foundation's State Health Facts. Data Source: Kaiser Family Foundation estimates based on the Census Bureau's March 2016 Current Population Survey (CPS: Annual Social and Economic Supplement).

⁴ U.S. Census Bureau; 2010-2014 American Community Survey 5-Year Estimates; generated by Liza Creel; using American FactFinder; <<http://factfinder2.census.gov>>; (14 September 2016).

⁵ Health Resources and Services Administration Data Warehouse. (n.d.). Health Professional Shortage Areas. Retrieved September 25, 2016 from <https://datawarehouse.hrsa.gov/topics/shortageAreas.aspx>.

⁶ Erickson, W., Lee, C., von Schrader, S. (2016). Disability Statistics from the 2014 American Community Survey (ACS). Ithaca, NY: Cornell University Employment and Disability Institute (EDI). Retrieved Apr 01, 2016 from www.disabilitystatistics.org; and American FactFinder, Disability Characteristics: 2014 American Community Survey (ACS) 1-Year Estimates (Table S1810), accessed April 1, 2015 from factfinder.census.gov.

⁷ The Kaiser Family Foundation's State Health Facts. Data Source: Urban Institute tabulations of 2013/2016 American Community Survey (ACS) data from the Integrated Public Use Microdata Series (IPUMS) from: Jennifer Haley, Genevieve Kenney, Robin Wang, Victoria Lynch, and Matthew Buettgens. Medicaid/CHIP Participation Reached 93.7 Percent Among Eligible Children In 2016, The Urban Institute, Washington, DC, August 2018.

⁸ The Kaiser Family Foundation's State Health Facts. Data Source: Markus AR, Andres E, West KD, Garro N, Pellegrini C. Medicaid Covered Births, 2008 Through 2010, in the Context of the Implementation of Health Reform. Womens Health Issues. Sept-Oct 2013; 23(5):e273-e280; and Erratum, Nov 2013; 23(6); e411.

⁹ The Centers for Disease Control and Prevention (CDC), National Vital Statistics Reports (NVSR), Vol. 67, No. 8: Births: Final Data for 2017, November 7, 2018.

program annually. A total of 590 cases of permanent childhood hearing loss were reported since 2011, representing an observed incidence rate of 1.6 per 1,000 live births.

Kentucky's Health Care System and UNHS: There are a total of 49 Kentucky hospitals that partner with the EHDI program to implement universal newborn hearing screening. The number of infants born in each of these hospitals ranged from one to 5,338 in 2017.¹⁰ While screening rates are high in all hospitals, there is variation in referral processes and follow-up rates across the state.¹¹ Infants who fail their newborn hearing screen are generally referred for local rescreening or to one of 52 diagnostic testing centers (including the 11 clinics operated by the Commission). Data from the Area Health Resource File indicate that there were 139 licensed audiologists in Kentucky in 2009 (range by county: 0-43) and 121 licensed ENT physicians that report seeing patients (range by county: 0-43), although there is no notation for which providers see pediatric patients or if these providers are actively practicing.¹²

Kentucky and UNHS Follow-up: The literature suggests that several factors may be associated with decreased likelihood of receiving follow-up services, including distance from specialty providers who perform diagnostic testing,^{13,14} severity of hearing loss,¹⁵ and parent education level.^{16,17} Many of these impact Kentucky families. Of those Kentucky infants who referred for follow-up in the last five years (n=13,220), 46% lived in a non-metropolitan county and over one-quarter resided in rural counties, and over half of those mothers had no more than a high school diploma (see Table 1). These data suggest that Kentucky families may be at greater risk of loss to follow-up. The population of infants that referred for follow-up was also racially diverse and varied on other demographic and socioeconomic characteristics including mother's education level (see Table 1).

¹⁰ Analysis of EHDI program data reported through KY Child data system.

¹¹ Analysis of EHDI program data reported through KY Child data system.

¹² Internal analysis of: *Area Health Resources Files (AHRF)*. 2015-2016. US Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Workforce, Rockville, MD.

¹³ Bush, M. L., Hardin, B., Rayle, C., Lester, C., Studts, C. R., & Shinn, J. B. (2015). Rural barriers to early diagnosis and treatment of infant hearing loss in Appalachia. *Otol Neurotol*, 36(1), 93-98. doi:10.1097/mao.0000000000000636

¹⁴ Oghalai, J. S., Chen, L., Brennan, M. L., Tonini, R., & Manolidis, S. (2002). Neonatal hearing loss in the indigent. *Laryngoscope*, 112(2), 281-286. doi:10.1097/00005537-200202000-00015

¹⁵ Spivak, L., Sokol, H., Auerbach, C., & Gershkovich, S. (2009). Newborn hearing screening follow-up: factors affecting hearing aid fitting by 6 months of age. *Am J Audiol*, 18(1), 24-33. doi:10.1044/1059-0889(2008/08-0015)

¹⁶ Bush, M. L., Hardin, B., Rayle, C., Lester, C., Studts, C. R., & Shinn, J. B. (2015). Rural barriers to early diagnosis and treatment of infant hearing loss in Appalachia. *Otol Neurotol*, 36(1), 93-98. doi:10.1097/mao.0000000000000636

¹⁷ Holte, L., Walker, E., Oleson, J., Spratford, M., Moeller, M. P., Roush, P., . . . Tomblin, J. B. (2012). Factors influencing follow-up to newborn hearing screening for infants who are hard of hearing. *Am J Audiol*, 21(2), 163-174. doi:10.1044/1059-0889(2012/12-0016)

Table 1. Demographic Characteristics of Kentucky Infants Overall and the Population that Refers for Follow-up Hearing Screening or Diagnostic Testing, 2011-2017

	KY Overall Infant Population	KY EHDI Refer Population
Infant Race		
White/Caucasian	66.3%	61.5%
Black/African American	8.4%	9.3%
Asian/Asian Indian	1.3%	1.0%
American Indian/Alaska Native	0.1%	0.1%
Native Hawaiian/Pacific Islander	0.1%	0.1%
Two or More Races	3.64%	4.6%
Hispanic	0.1%	0.7%
Other/Unknown	20.1%	22.6%
Infant Gender		
Male	51%	56.8%
Female	49%	43.2%
Geographic Residence		
Urban / Metropolitan	59.1%	53.3%
Suburban / Non-Metropolitan >20,000	18.1%	18.4%
Rural	22.8%	28.3%
Mother's Age		
Less than 18 Years	3.3%	7.6%
18-24 Years	35.7%	37.3%
25-34 Years	50.9%	45.6%
35-44 Years	9.9%	9.4%
45 or More Years	0.1%	0.1%
Mother's Education		
No High School Diploma	14.4%	23.2%
High School Diploma	29.7%	31.2%
Some College	23.5%	21.1%
Associate or Bachelor Degree	23.2%	18.2%
Graduate or Professional Degree	8.8%	5.7%
Unknown	0.3%	0.6%

The Kentucky EHDI Program also documents risk factor status, tracking fifteen risk factors and the presence or absence at birth. Documented risk factors include:

- Anoxia Present during Birth Admission
- Craniofacial Anomaly or Syndrome Present
- Cytomegalovirus Present, Mother or Baby Admission to NICU
- Maternal Exposure to Rubella
- Seizure(s) during Birth Admission
- Birth Weight Less than 2500g
- Five Minute Apgar Score of Three or Less
- Bilirubin Level Greater than or Equal to 18mg%
- Family History of PCHL
- Meningitis Present, Infant
- Ototoxic Medications during Birth Admission
- Persistent Pulmonary Hypertension (PPHN) Present during Birth Admission
- Sepsis during Birth Admission
- Persistent Pulmonary Hypertension (PPHN) Present during Birth Admission
- Sepsis during Birth Admission
- Maternal Syphilis Diagnosis

Table 2 describes the population of infants identified with one or more risk factors since 2011. A total of 25,999 infants were reported to have at least one risk factor for hearing loss and over 9,000 infants had more than one risk factor at birth.¹⁸ Knowledge of risk factor status is especially important for community pediatricians who are responsible for monitoring the health of infants as they grow. In addition, this represents a population of the EHDI target population that may be at risk for delayed-onset hearing loss.

Table 2. Risk Factors Reported for Kentucky Infants, 2011-2017

Risk Factor	# of Infants for whom Risk Factor was Reported
Anoxia Present during Birth Admission	58
Craniofacial Anomaly or Syndrome Present	1,099
Cytomegalovirus Present, Mother or Baby	62
Admission to NICU, >5 Days	27,264
Maternal Exposure to Rubella	21
Seizure(s) during Birth Admission	258
Birth Weight Less than 2500g	12,488
Five Minute Apgar Score of Three or Less	259
Bilirubin Level Greater than or Equal to 18mg%	215
Family History of PCHL	4,288
Meningitis Present, Infant	65
Ototoxic Medications during Birth Admission	3,400
PPHN Present during Birth Admission	298
Sepsis during Birth Admission	427
Maternal Syphilis Diagnosis	74

Stakeholder Perceptions of UNHS in Kentucky: In the summer of 2016, the Kentucky EHDI Program launched stakeholder surveys in an effort to gather input from stakeholder groups across the state. The surveys ask specifically about their role as providers or their experiences as families, and requesting input on areas of improvement. A sample of results, focusing on data from the 2017 survey where there were a substantial number of respondents, are provided here.

The 2017 survey had a total of 26 parent respondents. Ninety-three (93) percent were aware that their child had been screened, and two respondents indicated that they were never told the screening would occur before it was completed. About 10 percent of respondents were not aware at the time of discharge that their child needed additional hearing tests, and only 43 percent reported that their primary care doctor talked to them about the results of their baby's newborn hearing screen. The majority of parents reported that their baby's follow-up appointment was scheduled either before hospital discharge (21%) or was confirmed by letter post-discharge (18%). Around 25% of respondents called to schedule their own appointment. While most parents did not report problems scheduling follow-up appointments, some noted confusion,

¹⁸ Analysis of EHDI program data reported through KY Child data system.

inconvenient appointment times/locations, and lack of childcare as barriers. Over half of parents indicated that it took two to three visits before there was diagnostic confirmation related to hearing loss. When asked about challenges encountered during the follow-up period, parents noted the following: their doctor told them the screen result was nothing to worry about or they were told to wait until their baby was older to get another test, they had to visit several places to obtain diagnosis, they were given too little information or were unsure how to navigate the system, and that insurance would not cover the tests.

About 42% of parents felt they had received adequate information about their child's hearing loss from the hospital where the child was screened. Alternatively, 64% of parents felt they received adequate information from the provider that performed diagnostic evaluation and 80% felt they received adequate information from their child's early intervention provider. *Approximately 53% felt they received enough information from their pediatrician or primary care provider, an improvement from only 16% in 2016.*

Overall, the results of the parent survey indicate that the need for information and services for parents and families persists. Perhaps the most apparent need is for information to support the relationship between families and their child's primary care provider.

Physicians responding to the surveys (n=59) work in a variety of settings including hospitals, Federally Qualified Health Centers, private offices, academic and charity clinics. Only 22% reported accessing resources from the KY EHDI program or website, while more (58%) access resources from national websites such as the AAP or NCHAM. Others reported finding information about hearing loss from training curriculums, the peer-reviewed literature, or consultations with specialty providers. Approximately 47% of physician respondents had received information about potential risk factors for infants in their practice (an increase from 41% in 2016), but 32% were not aware or unsure of the recommendations for monitoring infants and toddlers with risk factors for progressive or delayed onset hearing loss.

The physician respondents were largely unaware of the EHDI mission and purpose (32% not familiar at all), the 1-3-6 Goals (45%), contact information for EHDI (45%), and the EHDI website (62%), although each of these improved compared to 2016 survey data. These findings suggest that physician outreach may be key to engaging community providers with the EHDI program. Indeed, several providers, when asked for recommendations for the EHDI program, indicated they would appreciate more information about EHDI and more resources related to treating patients with or at risk for hearing loss.

Across all provider respondent types (hospitals, physicians, audiologists, and early intervention), a majority indicated that the following needed improvement: referral processes for diagnostic evaluation, referral process for early intervention, strengthening enrollment and services in early intervention, and training and education of all stakeholders. These needs align closely with those proposed in this grant.

Altogether, the needs assessment highlights several overarching needs in EHDI in Kentucky:

- 1) The state is geographically and racially diverse, suggesting the need for evaluating and ensuring the inclusivity and diversity of the EHDI system activities.

- 2) While screening rates are high, Kentucky families face challenges related to accessing information about hearing loss, identifying sources for follow-up, and accessing those needed services. Some of the barriers to access are socioeconomic, including lack of transportation and childcare. Efforts to engage families may present opportunities to address disparities in access to health services.
- 3) Stakeholder engagement, with a focus on training and education, is a primary area in need of improvement in Kentucky, as identified by stakeholders themselves. They also identified opportunities to further engage the state early intervention program.

METHODOLOGY

As stated in the Funding Opportunity Announcement (FOA), HRSA-20-047, the overall Health Resources and Services Administration (HRSA) purpose for the Program is to “support comprehensive and coordinated state and territory EHDI systems of care so families with newborns, infants, and young children up to 3 years of age who are deaf or hard of hearing (DHH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI)”.

The six HRSA Program objectives are aimed at supporting the development of state/territory programs and systems of care to ensure that children who are DHH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development.

Using the 2017 CDC EHDI Hearing Screening and Follow-up Survey results as baseline:

1. Increase by 1 percent from baseline per year, or achieve at least a 95 percent screening rate, whichever is less, the number of infants that completed a newborn hearing screen no later than 1 month of age. For 2017, the Kentucky screening rate was 96.58%.
2. Increase by 10 percent from baseline, or achieve a minimum rate of 85 percent, the number of infants that completed a diagnostic audiologist evaluation no later than 3 months of age. For 2017, the Kentucky rate for this measure was 86.74%
3. Increase by 15 percent from baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age. For 2017, the Kentucky rate for this measure was 20.24%

Using data collected from year 1 as baseline:

1. Increase by 20 percent from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age.
2. Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.
3. Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.

KY EHDI’s efforts to meet the HRSA Program goals/objectives described above will focus on:

- 1) Increasing pediatric health care professional knowledge and engagement; 2) improving timely access to screening, diagnostic evaluation and early intervention services; and, 3) improving family engagement and partnerships with EHDI key stakeholders.

1. Lead efforts to engage and coordinate all stakeholders in the state EHDI system to meet the goals of this program

KY EHDI plans to engage and coordinate stakeholders in the EHDI system in several ways in an effort to improve the overall system. First, KY EHDI will continue the use of KY CHILD for the reporting of hearing screening results by birthing centers or other providers as well as for the reporting of diagnostic results by audiologists. KY CHILD data will continue to be utilized for the assessment of birthing centers' adherence to screening and reporting guidelines as well as for the assessment of audiologists' adherence to testing, reporting and referral guidelines. Direct contact will be made with any reporting facility or provider that is not meeting the screening, reporting or referral guidelines so as to reinstruct them on the 1-3-6 goals. Notification letters will continue to be sent to primary care providers of children on their caseload who require follow-up due to a referral on the newborn hearing screen or for a risk factor. To build upon the current screening infrastructure in KY, EHDI will consult with the Early Childhood Branch Manager in the Department of Public Health to develop a strategy to expand the infrastructure for screening children up to age 3. KY EHDI will also consult with the Kentucky Head Start State Collaboration Office in the Department of Early Education to develop a strategy to assess the current level of infrastructure regarding routine hearing screening for children up to age 3. Advice will be sought from The Kentucky Chapter of the American Academy of Pediatrics regarding ways in which pediatricians can be educated about the importance of routine hearing screening in order to support the screening efforts. Utilizing the information gleaned from the above activities, KY EHDI will develop a plan to expand infrastructure for hearing screening for children up to age 3 by the end of year 2. KY EHDI will also complete an annual accounting of current partnerships that exist among the various stakeholder organizations and programs as well as potential partnerships that do not currently exist. This information will be used to identify current partnerships that could be expanded or the potential to create new partnerships. Through an MOU with the Kentucky Chapter of Hands & Voices, KY EHDI will seek to assess current gaps in family engagement and family support, generate a list of at least three possible initiatives to address project goals and objectives, and complete one QI initiative, annually, to address project goals and objectives aimed at increasing family engagement and family support in the EHDI system. This same format will be used in partnership with the Early Childhood Branch Manager to assess gaps in the system, generate a list of initiatives and complete one QI initiative, annually, to address project goals and objectives aimed at improving EI referral and/or enrollment.

KY EHDI has an active Advisory Board comprised of representatives from 15 different stakeholder groups. The Board will continue to convene approximately every three months to assess and advise on programs, objectives and strategies for improvement. The Advisory Board is currently comprised of 25% parents and this level will be maintained. The Advisory Board currently has only one adult member who is deaf or hard of hearing. KY EHDI will seek to increase the level of participation on the board by adults who are deaf or hard of hearing. The Advisory Board will also seek to increase the number of participating pediatricians as there are currently only two active pediatricians on the Board due to recent resignations. The KY EHDI Advisory Board will continue to develop and implement objectives or strategies by professionals as well as by parents and family-oriented

organizations to advance EHDI program goals. The KY EHDI Advisory Board will seek to bring in a speaker or expert on diversity and inclusion within the state of Kentucky during year 1. The EHDI database will be used to identify potential diversity and inclusion needs across the state based on the analyzation of such factors as zip code, race, ethnicity, gender and family structure. The EHDI Advisory Board will use strategies provided by the speaker/expert and the information gleaned from the database report to develop a plan for addressing diversity and inclusion needs within the system.

The KY OCSHCN EHDI program currently has a state maintained website. An assessment of the current website in regard to the information and resources available will be completed on at least an annual basis. Additional information and resources will be added to the website as any gaps are identified. The website will be promoted through internet and social media resources available within the agency on an ongoing basis.

2. Engage, educate and train health professionals and service providers in the EHDI system

KY EHDI will train midwives and physicians on: the importance of meeting 1-3-6 recommendations; the need for continual screening, diagnosis, and intervention up to age 3; benefits of patient and family-centered medical home; the importance of providing current and accurate information to families, including decisions about the full range of assistive technologies and communication modalities; program specific EHDI information. KY EHDI has received interest from the KY Chapter of the National Association of Certified Professional Midwives (NACPM) to present to their members about EHDI, including the newborn hearing screening process and state requirements, screening techniques as well as funding opportunities for securing screening equipment if any of their members so desire. A presentation by KY EHDI to the KY Chapter of NACPM will be developed and completed by the end of year 1. KY EHDI will also explore the feasibility of offering continuing education credits to physicians through a webinar focused on program objectives. If it is determined by the end of year 1 to be a feasible task, KY EHDI will develop and publish a webinar on EHDI program objectives to target health professionals and service providers. KY EHDI has historically had a booth at the KY AAP meeting and this will be applied for each year of the grant. On an annual basis, KY EHDI will evaluate ways to collaborate, as appropriate, with the HRSA-18-069 National Resource Center for Patient/Family-Centered Medical Home. Collaboration will be sought where appropriate.

3. Strengthen capacity to provide family support and engage families with children who are DHH as well as adults who are DHH throughout the EHDI system

KY EHDI has several goals for attempting to strengthen its capacity for serving families and adults who are DHH across the state. The KY EHDI Advisory Board is comprised of 25% parents and/or individuals who are DHH. As members of the Advisory Board, parents and adults who are DHH have direct input into the goals set and tasks undertaken by EHDI stakeholders in the state. This level of representation will be maintained throughout the funding period and a particular focus will be applied to recruiting more adults who are DHH to join the Advisory Board. In addition to spreading news through the EHDI Advisory

Board, the use of the OCSHCN website and social media outlets will be pursued in order to reach families and adults who are DHH about EHDI system activities. KY EHDI will also consult, at least annually, with the HRSA-20-051 recipient for resources, technical assistance, training, education, QI and evaluation to strengthen the infrastructure and capacity for family engagement and family support in the state.

Through an MOA, KY EHDI will partner with the KY Chapter of Hands and Voices in multiple ways to expand the reach of services and participation numbers of families and adults who are DHH. First, a training for families will be developed and conducted on advocacy with medical and therapeutic providers. This training will be designed to educate more recently diagnosed families so they can more competently navigate the healthcare system and advocate effectively for their children. The possibility of holding a one-day conference for families and medical/therapeutic/educational stakeholders will also be explored. A potential structure for the conference would be where the families and stakeholders come together for some presentation(s), but also have break-out sessions focused toward family or professional areas. A conference in this format would have the intention of facilitating partnerships among families, health care professionals, and service providers to ensure effective family engagement. Through the MOA, KY EHDI will provide funding to Hands and Voices for their continued activities across the state that engage families and adults who are DHH. During the current funding period, the KY Chapter of Hands and Voices has established a Guide By Your Side program with six trained guides and developed an adult DHH program that has effectively reached out to families on several occasions. During the proposed program period, Hands and Voices anticipates hiring an adult DHH coordinator in order to expand their program as well as hire, train and support more Guides throughout the state. In order to address the stated goals of increasing enrollment in family-to-family and adult DHH-to-family support services by the age of 6 months and 9 months, respectively, a referral process from providers to Hands and Voices will be explored. For the purposes of these goals, “enrollment” will be defined by person to person contact. Hands and Voices uses a database program (Zoho Creator) that can be constructed to track any data sets they so choose. Hands and Voices records the date of birth of the child, date of contact, and date of the last file update. For events, families typically preregister so the number of new versus established contacts is largely known beforehand, however, they can register and track families at the event site as well. For events that include outreach with adults who are DHH, the number of contacts with them by families can also be tracked.

4. Facilitate improved coordination of care and services for families and children who are DHH between EHDI and early childhood programs including the IDEA Part C program

KY EHDI and Part C have historically had limited coordination of care and services due to FERPA restrictions noted by Part C. At this time, the KY Part C program, First Steps, does conduct otoacoustic emissions screenings on children referred to their program when possible. These screening results are sent to the EHDI program. There is also an agreement between EHDI and Part C that the OCSHCN is the primary referral site for any diagnostic hearing evaluations needed during the assessment process. Although hearing screens are

likely occurring in other locations in early childhood (Early Head Start, etc.), these results are not typically reported to EHDI. To address the facilitation of improved coordination, an assessment will be completed in the first eight months regarding the coordination with EHDI across early childhood programs, including Part C. From this assessment, a plan will be developed by the end of year 1 and implemented during the following years to increase coordination.

5. Education and technical assistance

KY EHDI will partner with the KY Chapter of Hands and Voices to identify a family member to attend the EHDI Annual Meeting. KY EHDI has budgeted to send two staff members to the EHDI Annual Meeting.

KY EHDI has had a strong relationship with the current National Technical Resource Center in the past. KY EHDI will continue to consult with the NTRC to implement various initiatives listed in this funding of opportunity announcement and outlined in the work plan. EHDI staff will also attend webinars and other educational offerings through the NTRC in order to obtain needed resources to strengthen the services provided by the EHDI program.

In regard to project sustainability beyond the period of federal funding, the OCSHCN EHDI website is already established and will continue to be supported and maintained by OCSHCN staff. The EHDI Advisory Board can function as a standalone entity and could continue to convene with the use of OCSHCN facilities. Hands & Voices indicated they will increase their efforts to solicit donations from community partners and seek additional grant funding opportunities to continue family engagement and family support activities.

WORK PLAN

The EHDI Program goals and objectives were developed with input from the EHDI Advisory Committee and partner organizations, including Hands and Voices, and the OCSHCN Medical Director and Information Officer. The activities in the proposed work plan are designed to accomplish the goals and objectives of the FOA and improve Kentucky's EHDI program's services to children and families. The grant activities will take place over a 4-year period (4/1/2020 – 3/31/2024) and are described below. A comprehensive work plan is included in Attachment 1.

Goal 1: Engage and coordinate all stakeholders in the state EHDI system to meet the goals of this program.

Objective 1.1: Provide a coordinated infrastructure to ensure all newborns meet timely 1-3-6 goals

Objective 1.2: Develop a state plan to expand infrastructure for screening children up to age 3 by the end of year 2

Objective 1.3: Establish and maintain partnerships for referral, training and information sharing with stakeholders with an update completed annually

Objective 1.4: Convene a state EHDI advisory committee, approximately once every 3 months, to advise on programs, objectives and strategies

Objective 1.5: Develop a plan to address diversity and inclusion in the EHDI system by the end of year 2

Objective 1.6: Develop and implement a strategy to monitor and assess program performance in meeting program purpose and objectives that would contribute toward continuous quality improvement (QI) throughout the period of performance

Objective 1.7: Develop, maintain and promote a website/webpage for the state

Objective 1.8: Plan for project sustainability

Goal 2: Engage, educate and train health professionals and service providers in the EHDI system.

Objective 2.1: Conduct outreach and education to health professionals and service providers in the EHDI system

Objective 2.2: Collaborate, as appropriate, with the HRSA-18-069 National Resource Center for Patient/Family-Centered Medical Home Recipient

Goal 3: Strengthen capacity to provide family support and engage families with children who are DHH throughout the EHDI system.

Objective 3.1: Engage families throughout all aspects of the project

Objective 3.2: Conduct outreach and education to inform families about opportunities for involvement within the EHDI system and addressing challenges to and providing solutions for the EHDI system

Objective 3.3: Facilitate partnerships among families, health care professionals and service providers to ensure providers understand the best strategies to engage families

Objective 3.4: Support to statewide family-based organization(s) to support family engagement and family support activities

Objective 3.5: Consult with the HRSA-20-051 recipient for resources, technical assistance, training, education, QI and evaluation to strengthen the infrastructure and capacity for family engagement and family support in the state

Goal 4: Facilitate improved coordination of care and services for families and children who are DHH through the development of mechanisms for formal communication, training, referrals, and/or data sharing between the state EHDI program and early childhood programs including the IDEA Part C program.

Objective 4.1: Demonstrate evidence of planning and stakeholder engagement through development of a written plan by the end of year 1 and demonstrate evidence of formal communication, training, referrals and/or data sharing by end of year 3

Goal 5: Education and technical assistance.

Objective 5.1: Provide support for two staff and one parent to participate in the Annual Early Hearing Detection and Intervention Meeting

Objective 5.2: Work with the HRSA-20-048 program recipient (the EHDI Technical Resource Center (NTRC)) to implement the various initiatives listed in the NOFO and outlined in the work plan

RESOLUTION OF CHALLENGES

Kentucky faces several challenges in implementing this work plan; however, KY EHDI has developed strategies to address each one.

One of the most significant challenges KY will face will be in engaging physicians in the outreach activities. KY EHDI has attempted to engage physicians in other initiatives in the past and have been largely unsuccessful. In an attempt to engage physicians, KY EHDI will be exploring the possibility of offering continuing education credits to physicians for their participation in an online seminar or possibly in a one-day multidisciplinary conference. The incentive of continuing education credits may increase physician participation leading to an expected improvement in their knowledge of serving families and patients who are deaf or hard of hearing.

Another significant challenge will be expanding the mechanisms for data sharing between EHDI and Part C. Limitations in sharing patient-specific referral and enrollment data have negatively impacted EHDI's knowledge about specifically how many children with hearing impairment are receiving services and whether the intervention was begun in a timely manner. Previous discussions, however, regarding the use of release forms signed by parents in order for EHDI to obtain this information have held some promise.

Kentucky's largely rural environment has restricted the ability of family support organizations to develop a strong statewide network of programs and services are largely offered in the three pockets of mostly urban areas (Lexington, Louisville and Northern Kentucky). Family organizations in KY have limited infrastructure to develop programming that can overcome the geographic challenges due to financial constraints, and therefore, even with the financial assistance available through this funding opportunity, most family support organizations have been unable to commit to large projects. To address this, KY EHDI has reached out to the

Kentucky Chapter of Hands and Voices to be the sole recipient of the family engagement funding available in this funding opportunity. With the increase in funding, Hands and Voices will be able to recruit and train more Guides for the Guide By Your Side program, grow their adult DHH outreach program, and offer more events across the state.

The last major challenge is that of sustainability. As a state government agency, budget issues are pervasive; however, KY EHDI has a history of being able to incorporate successful processes into regular practice despite budgetary issues. One strength for the KY EHDI program in this area is that EHDI is contained within the Office for Children with Special Health Care Needs (OCSHCN), KY's Title V agency, and therefore areas in which EHDI strategies are filling a gap in available services are able to be sustained through the MCH priority of remediating these gaps. The work that will be completed on the EHDI website in pursuit of this grant's goals, will be sustainable through the OCSHCN. Additionally, for some of the proposed work plan activities, such as the work through Hands and Voices, they are committed to finding additional funding sources currently so as not to rely solely on the money available through this grant.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

The KY EHDI evaluation team will conduct a program evaluation across the four-year project period and will draw on the KY EHDI logic model (see Attachment 1), the Work Plan (see Attachment 1), and the methodology section of this narrative. The KY EDHI program evaluation will employ the Centers for Disease Control and Prevention (CDC) Framework for Program Evaluation in Public Health (see Figure 1) as a conceptual model to guide the evaluation.¹⁹ A key strength of this evaluation model is that each step informs latter steps, thus offering evidence for program improvement or adaptation, and potentially the expansion of successful initiatives. The model also encourages stakeholder engagement throughout the process.



Figure 1. CDC Framework for Program Evaluation
Source: <http://www.cdc.gov/eval/framework/>

The evaluation will focus on the evaluation design, gathering evidence, justifying conclusions, sharing lessons learned, and engaging stakeholders, in hopes that the outcomes identified through

¹⁹ <ftp://ftp.cdc.gov/pub/Publications/mmwr/rr/rr4811.pdf>

the evaluation will inform future KY EHDI program decisions. Throughout the evaluation, the KY EHDI evaluation team will engage with the KY EHDI program staff and advisory committee to ensure standards are being met and relevant questions can be answered.

Proposed Project Goals and Objectives

The evaluation will measure both process and impact outcomes for each of the five overarching project goals. Under each of the five program goals, the evaluation will address the following aims:

1. The extent to which the program was implemented as planned (process evaluation).
Process measures include (among others listed in the Work Plan):
 - a. Participation in meetings with stakeholder groups (Early Childhood Branch Manager, KY AAP, etc)
 - b. Development of proposed objectives or plans to address stated goals
 - c. Development of an educational webinar on the EHDI program
 - d. Development of a one-day conference for families and professional stakeholders
 - e. Presentation to the EHDI Advisory Board by a speaker or expert on diversity and inclusion within the state of KY by the end of year 1
 - f. Completion of an EHDI database report to identify potential diversity and inclusion needs across the state
 - g. Development of a plan for addressing diversity and inclusion needs within the EHDI system by the end of year 2
 - h. Identification of at least one gap in the EHDI system for family engagement and family support
 - i. Development of possible QI initiatives to improve family engagement and family support in the EHDI system
 - j. Identification of at least one gap in the EHDI system for EI referral and/or enrollment
 - k. Development of at least two possible QI initiatives to improve EI referral and/or enrollment
 - l. # of additional documents or resources added to the KY OCSHCN EHDI website
 - m. # of promotional activities completed for the KY OCSHCN EHDI website
2. The extent to which the program achieved its intended outcomes (impact evaluation).
Outcome measures include (among others listed in the Work Plan):
 - a. Implementation of proposed plans
 - b. # of participants on the Advisory Board
 - c. # of pediatricians recruited to sit on the Advisory Board
 - d. # of adults who are DHH recruited to sit on the Advisory Board
 - e. # of infants enrolled in family-to-family support services by 6 months of age
 - f. # of infants enrolled in adult DHH consumer-to-family support services by 9 months of age
 - g. # of family engagement and family support activities implemented
 - h. # of participants for the educational webinar on the EHDI program
 - i. Implementation of a one-day conference for families and professional stakeholders

- j. Completion of one QI initiative, annually, to address project goals and objectives aimed at increasing family engagement and family support in the EHDI system
- k. Completion of one QI initiative, annually, to address project goals and objectives aimed at improving EI referral and/or enrollment
- l. # of additional visitors to the website following promotion activities

Data Collection and Outcomes

For each of the program goals, the evaluation team will collect and analyze data from existing EHDI reports. The Work Plan in Attachment 1 includes details about each proposed measure, baseline timeframe, and data source. The evaluation will use a combination of primary and secondary data sources to measure outcomes. Some sources of data will be provided to the evaluation team directly by the KY EHDI program staff. These include program documents (e.g. Advisory Board meeting minutes and attendance logs) and screening and follow-up data submitted by hospitals and diagnostic centers through the KY CHILD data system. Other data will be collected prospectively by members of the evaluation team, including data tracked through Hands and Voices for enrollment numbers and outreach activities.

Baseline data are already available for several outcome measures. For example, multiple years of screening, referral, and diagnostic data are available through the KY CHILD data system. Stakeholder knowledge of the EHDI program and the JCIH 1-3-6 recommendations was assessed in 2016 using a web-based survey and will provide a baseline for understanding changes in awareness and knowledge moving forward. Finally, CDC EHDI (Hearing Screening and Follow-up Survey) HSFS data from 2017 will be used as baseline data when applicable. Where baseline data are not available, baseline will be collected program year one.

Dr. Liza Creel at the University of Louisville School of Public Health and Information Sciences has worked with the KY EHDI program since 2016. She had led efforts to analyze existing data on hearing screening implementation and gather stakeholder input on the program. Dr. Creel has extensive experience in newborn screening research through her work with the HRSA-funded regional genetics collaboratives and in her doctoral dissertation. She has led the work on conducting annual stakeholder surveys targeting five major stakeholder groups: parents and families, hospitals, audiologists, physicians, and early intervention providers. These surveys were originally launched in 2016 and will maintain questions related to knowledge and awareness of the KY EDHI program. They will also ask respondents for input on strengths, weaknesses, opportunities, and challenges within the program.

Analyses

Where possible, the evaluation will look at program outcomes longitudinally, comparing multiple years of data to determine temporal trends and statistical changes. Specific analytic methods will depend on the outcome of interest. For example, enrollment numbers for family-to-family and adult DHH consumer-to-family support services will be assessed on at least an annual basis to evaluate the progress KY EHDI is making toward reaching two of the stated program objectives.

ORGANIZATIONAL INFORMATION

Since 1924, the Office for Children with Special Health Care Needs (OCSHCN) has provided care for children with physical disabilities. As the Title V agency for KY, the OCSHCN receives and administers initiatives and submits biannual reports in accordance with stated guidelines as recipients of Maternal and Child Health Block Grant MCHB funding. The mission of the OCSHCN is to enhance the quality of life for Kentucky's children with special health care needs through direct service, leadership, education and collaboration. The vision is: "To be a visible leader in supporting the highest quality of life for Kentucky's children with special health care needs and their families through collaboration and facilitation of an easily accessible community based system of support." The guiding values are: best practices, collaboration, communication, empowerment, family centered, and respect. The goals are: education, expansion and quality improvement. Services include case management, financial assistance and evaluation and treatment in the following specialty clinics: Asthma, Autism, Cerebral Palsy, Craniofacial Anomalies, Eye, Cardiology, Neurology, Neurosurgery, Scoliosis, Spina Bifida, Cleft Lip & Palate, Cystic Fibrosis, Hemophilia, Orthopedic, Otology, and Plastic Surgery. The OCSHCN has also expanded services to partner with the state foster care system to provide needed medical case management for medically fragile foster care children and all other children in the foster care system as needed. Eleven regional offices and six satellite clinics provide direct service to eligible children across the state. OCSHCN staff assists families in obtaining appropriate and quality care to meet their children's needs. The state's Early Hearing Detection and Intervention (EHDI) program, housed within the OCSHCN Audiology-EHDI Branch has the responsibility to manage the newborn hearing screening program, monitor timely and appropriate follow-up diagnostic services for those who do not pass the physiologic newborn hearing screening, and subsequent referral and entry into early intervention for those eligible infants who have confirmed hearing loss.

The passage of House Bill 706 mandated Universal Newborn Hearing Screening in Kentucky in July 2000. OCSHCN was identified as the lead agency for development, implementation, tracking, reporting and surveillance. As a condition of continued licensure, hospitals in Kentucky with 40 or more births annually were mandated to conduct physiologic newborn hearing screenings. KRS 211.647 mandates that birthing hospitals forward Hearing Screen Reports that indicate a potential for hearing loss on infants to the OCSHCN. It also states that the OCSHCN, upon receipt of an auditory screening report of an infant from a hospital, shall review each auditory screening report that indicates a potential hearing loss. OCSHCN has developed online entering of this information through a collaborative agreement with the Centers for Disease Control and Prevention. The statewide integrated KY CHILD (Certificate of Birth, Hearing, Immunization and Lab Data) program has a front page interface with shared demographic information and then is transferred to managing programs respectively. The hearing application is forwarded to the OCSHCN. Within 3 business days, the OCSHCN notifies the parents by mail of the need for a follow-up evaluation for their child and includes a list of approved providers.

The Audiology/Early Hearing Detection and Intervention branch of OCSHCN has applied for grant funding, been awarded and successfully implemented initiatives and reports to both the Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA-

MCHB) and the Centers for Disease Control and prevention since April 2000 and currently is working with both entities.

Original legislation (House Bill 706) did not require follow-up reporting from diagnostic audiologists, primary medical care providers or early intervention providers. In 2009, House Bill 5 passed which expanded KRS 211.647 and required audiologists as a condition for inclusion on an Approved Audiological Assessment and Diagnostic Centers list to agree to meet best practices for pediatric audiology as defined in the American Speech-Language Hearing Association (ASHA) Guidelines for Assessment of Children Ages 0-3 years and to submit results of all audiological evaluations of infants and toddlers to age 3 within 24 hours of the evaluation. The EHDI program within OCSHCN promulgated regulations to define and implement this new statute. The regulations passed the Joint House and Senate Health and Welfare Committee and were fully implemented January 1, 2010. Expansion of the KY CHILD interface application allowing diagnostic audiologists to apply, obtain authorization and training to submit diagnostic follow-up to EHDI electronically was instrumental in obtaining buy in. (See Attachment 13: Infant Audiological Assessment and Diagnostic Centers List). In 2014, the regulation was amended to state that participating audiologists must conform to JCIH best practice standards as well as either ASHA or the American Academy of Audiology. Additionally, the new amendment requires only electronic submission of hearing evaluation results from approved audiologists and not faxed or mailed paper copies.

Several states in EHDI regional meetings and those in the National Initiatives for Children Healthcare Quality (NICHQ) learning collaborative reported reducing loss to follow-up after hospital discharge by initiating phone calls to families to assist in scheduling appointments or to remind them of the necessity of keeping a scheduled appointment. Utilizing their experience OCSHCN funded a part-time employee (PTE) follow up coordinator in 2008 and expanded the position to a full-time employee (FTE) in May 2010. An additional PTE to aid the full time follow up coordinator was hired in 2014 and is a parent of a child identified as Deaf or Hard of Hearing. These positions have resulted in the predicted outcome of reducing loss to follow-up between hospital referral and diagnostic audiology services.

The Kentucky OCSHCN's scope of activities and organizational structure contribute to our ability to conduct program requirements and meet program expectations in the following ways:

- The organizational structure of aligning the EHDI Branch and the Audiology Branch facilitates better communication, cooperation and improved service delivery.
- Audiology staff act as consultants for community hospitals, conduct annual reviews to assess data submissions, statistics, staff changes, and training/equipment needs. This regular contact and continuous monitoring of data with focus on quality improvement enhances collaboration and support of EHDI at the initial screening/referral process.
- Experienced Project Directors, EHDI Coordinators, and fiscal staff in managing grant initiatives, collaboration among stakeholders and reporting to federal partners.
- All eleven OCSHCN locations throughout the state have staff and/or contracted Audiologists to provide follow-up evaluation/intervention to infants who failed to pass the newborn hearing screening.

- Audiology practitioners with experience assessing infants and pediatric populations have collaborated by completing surveys prior to being listed on the resource list to be disseminated by EHDI to families and by hospitals and other health care providers.
- Approved audiology practitioners agreed to enter follow-up online as a condition of remaining on the referral list.
- The OCSHCN mission, vision, guiding values and goals compel us to provide the highest quality service utilizing best practices in a family centered model to all children with special health care needs in Kentucky.
- The alignment of OCSHCN and the Department for Public Health (lead agency for the Part C Early Intervention program – “First Steps”) within the same state Cabinet (Cabinet for Health and Family Services) also facilitate better communication, collaboration and improved service delivery.

The Commonwealth does not currently have a fully functional integrated child health data system; however, with the advent of KY CHILD and other e-Health initiatives Kentucky is definitely moving in that direction. KY CHILD was developed by the Cabinet for Health and Family Services, Office of Information Technology in collaboration with the Department for Public Health and the OCSHCN. It was initiated statewide in late 2006 in all 60 (currently 49) birthing facilities. It is a web based application that integrates and automates the collection of health and human services data pertaining to the birth of newborns in the state. The goals achieved by KY CHILD include implementation of an interface for integrated data collection with adequate data edits and validation to ensure accuracy of data; provides automatic reporting and printing capabilities for Certificate of Live Birth, Certificate of Still Birth, Newborn Hearing Screening, Metabolic Screenings, and Congenital Critical Heart Disease screenings; and automatic submission of back-end systems for registration of birth, as well as case management for Newborn Hearing and Metabolic Screening events. The UNHS (Universal Newborn Hearing Screening) data is automatically transmitted to the OCSHCN, Early Hearing Detection and Intervention branch for case management of referrals. These are transferred electronically into the Computer Utilization Program (CUP) where EHDI staff de-duplicates and disseminates information to families.

Follow up diagnostic audiology appointments scheduled in KY CHILD with audiologists prior to hospital discharge are transferred into the diagnostic audiologists’ “pending audiology appointments” view within KY CHILD. EHDI staff also links families to warranted services and monitors the follow-up received from diagnostic audiologists, medical homes and early interventionists. Reports received in other formats than KY CHILD electronic transfer are entered into the data base by the EHDI follow-up coordinators.

KY CHILD is a working component of an integrated system. Continued endeavors to increase its functionality are ongoing. Each newborn now has an established unique identifier. The functionality of KY CHILD has assisted in laying the foundation for other critical systems. The Kentucky Vital Events Tracking System (KVETS) is the foundation for data that’s created in the Kentucky Certificate of Birth, Hearing, Immunization and Lab Data System (KY-CHILD). The immunization and lab data collected consists of newborn metabolic screening. There are

other modules which feed data to the KVETS, such as Birth Index, Audiology Update Form (AUF), Accounting Correspondence Tracking (ACT) and Induced Termination of Pregnancy (ITOP). Internally, KVETS is utilized by the Office of Vital Statistics to perform amendments to birth, death and stillbirth data. KVETS is built on a scalable platform which allows for expedient and seamless module additions and enhancements.

In 2010, Kentucky began developing the Kentucky Health Information Exchange (KHIE) which is housed at the Cabinet for Health and Family Services (CHFS), is a secure, interoperable electronic network that supports statewide exchange of patient health information among healthcare providers across the Commonwealth. KHIE includes a master patient index, record locator service, security, provider/user authentication, logging and audits. The system includes patient demographics, lab results, radiology and other transcribed reports, historical patient diagnoses, encounters, and procedures. KHIE acts as data intermediary for public health reporting to the state immunization and cancer registries, reporting of syndromic surveillance data and reportable labs/diseases. KHIE also offers a community record (virtual health record) for care coordination. The EHDI program has been in contact regarding adding hearing screening information to KHIE, however, this project is not yet ready to support this feature.

OCSHCN will take several steps to ensure fiscal accountability with this grant. Hands and Voices has indicated they will have an accountant on staff to handle their finances and timely invoicing for reimbursement. With this process in place, they should be aware of any monetary issues that may arise and can reach out to OCSHCN in a timely manner. For the OCSHCN, the project director will detail the submitted invoices in her submission to the finance department. The finance department will carefully review submitted invoices to ensure none are overlooked. The project director will also receive monthly accountings of the expenditures on the grant for review. Any expenditures out of the grant will be reviewed by the project director and the finance department will be consulted regarding any missing or unexpected allocations. Any mistakes will be rectified prior to completing the FFR for that program period.