PROJECT SUMMARY: In April 2008 the EHDI Regional Coordinators began collaboration with statewide partners to implement quality improvement initiatives aimed at reducing "loss to follow-up" at each of these critical junctures: 1) between referral on UNHS and outpatient re-screening; 2) between re-screening and diagnostic audiology; and 3) between diagnostic audiology and enrollment into early intervention. In the initial year of the grant initiatives were tried as a potential "model of improvement". With evidence of success in the majority of the pilot hospitals and with parents and partners, during the second year of the grant beginning April 2009 the initiatives with modifications began to be replicated throughout the state. The pilot hospitals with the least evidence of success have also had the least technical support from the EHDI program due to staffing issues and changes. Information in the Experience to Date and Staffing sections of this document will identify current data and the obstacles encountered in some areas. With additional staff and updated hospital site evaluation criteria, these delays are expected to resolve. All birthing hospitals in the state; primary care providers or medical homes; and all providers on the Audiology Resource list will be monitored by EHDI for measurable changes in follow up.

Expansion during the second year of the current Early Hearing Detection, Diagnostics, and Intervention Project began April 1, 2009. Momentum accelerated when additional grant funds were awarded August 2009, providing fuel for the movement of the project to go statewide with the follow up coordination initiatives and to incorporate a structured parents as partners action plan. The underlying purpose of the grant as stated in the original project proposal is to focus on efforts to improve tracking and surveillance of infants who refer on the physiologic newborn hearing screen, and to decrease the number of these infants who are "lost to reporting" and truly "lost to follow up." With the Early Hearing Detection, Diagnosis and Intervention (EHDDI) Project, it is anticipated that a strengthened and streamlined system for families of newborns, following referral from Universal Newborn Hearing Screening, into diagnostic audiology, and into warranted early intervention services will result.

Consistent with the reduction of loss to follow-up goals, the purchase of audiology equipment for Title V CCSHCN offices ensures provision of infant hearing diagnostic evaluations as recommended by the Joint Committee on Infant Hearing 2007 (JCIH 2007), amplification verification analysis, and increase in accessibility to services across the state. Additionally, the passage of House Bill 5 in March 2009 provides a mandate for audiology diagnostic reporting and the subsequent promulgation of regulations for the statute, which coincides with the roll out of the electronic audiology update form and on line diagnostic reporting. The Kentucky Child Hearing, Immunizations, Laboratory Data (KY CHILD) project is a cooperative with CCSHCN and Cabinet for Health and Family Services Office of Information Technology (CHFS-OIT) to develop an online/electronic reporting system for diagnostic audiologists. Funding for this project is from the Centers for Disease Prevention and Control (CDC) grant, providing the vehicle for smooth transition of audiologists statewide in meeting the mandate for reporting on all diagnostics of newborns who refer on the newborn hearing screening.

Collaboration with stakeholders has been and continues to be strengthened. Intentional partnership planning has been initiated with the Kentucky Hands and Voices Chapter and with the Kentucky Commission on the Deaf and Hard of Hearing to work with CCSHCN parent consultants and EHDI program staff to provide human and financial support in developing

"Guide by Your Side" and providing resource packets to all families with newly diagnosed infants and toddlers. Continued cooperation with First Steps (IDEA Part C) and additional public/private stakeholders with a vested interest in Early Hearing Detection and Intervention enlarges the net while tightening the gaps. Obstacles encountered in attempting to meet the goals of collaboration have included the lack of a Memorandum of Agreement with First Steps (IDEA Part C). The lack of this agreement has two sources: 1. Unresolved legal issues regarding sharing of information 2. Change of leadership in First Steps program. A meeting with the new First Steps Director is scheduled in early December 2009.

PROJECT PROGRESS AND OBJECTIIVES: In March 2009 House Bill 5, sponsored by Representative Tom Burch (D)-District 30, passed in both the House of Representatives and the Senate and Governor Steve Beshear signed it into law on March 27, 2009. HB 5 expanded the Universal Newborn Hearing Screening mandate (House Bill 706, April 2000) to require audiologists to report diagnostic hearing results on all children from birth to three years of age. The Bill assigned CCSHCN responsibility for development of regulations to support the precepts of HB 5 and management of the "Infant Audiological Assessment and Diagnostic Centers". This legislation's infrastructure provides by the power of mandate incentive to reduce loss to follow up between the hospital screening and diagnostic evaluations that is related to lack of documentation. The KY CHILD web based application for audiologic diagnostic reporting provides the electronic mechanism to simplify reporting by completing evaluations through web based reporting, therefore decreasing turnaround time in reporting, and encouraging audiologists to elect to complete the requirements of the statute.

The principals of this legislation include: 1. Establishment of standards for "approved centers" based on accepted national standards including but not limited to the "Guidelines for the Audiologic Assessment of Children From Birth to 5 Years of Age" as published by the American Speech-Language-Hearing Association (ASHA) and the "Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs" as published by the Joint Committee on Infant Hearing (JCIH). 2. Maintenance of an approved infant audiological assessment and diagnostic centers list of that meet the standards established by the commission. 3. Voluntary participation (audiologists who choose not to complete application process will not be included on the list as an approved pediatric audiology provider.) 4. Agreement by audiology assessment and diagnostic centers to provide requested data to CCSHCN for each infant evaluated and on any newly identified children ages birth to three years with a permanent childhood hearing loss within 48 hours and make a referral to the Kentucky Early Intervention System point of entry. 5. Submission of documentation to CCSHCN of any referral made to the Kentucky Early Intervention System (First Steps). Referrals received by First Steps from a diagnostic center shall be considered a referral from CCSHCN. 6. Requirement that upon receipt of an audiologic evaluation containing evidence of a hearing loss to CCSHCN the EHDI program contact and provide information to parents, contact the child's primary care provider, and make a referral to First Steps within 48 hours of receipt of the information. 7. Promulgation of administrative regulations in accordance with KRS Chapter 13A to establish the standards for the centers.

The Kentucky Administrative Regulation 911 KAR 1:085 was amended, filed, approved and signed by Janie Miller, Secretary of The Cabinet for Health and Family Services. The proposed

regulation passed the Administrative Regulations Joint Committee on November 10 without opposition and the final hearing before the joint Health and Welfare Committee is scheduled in December 16, 2009. Full implementation is expected by January 1, 2010. In anticipation of approval, application packets are ready to be mailed to audiology sites across Kentucky and these will include necessary paperwork to access and use the online submission application through KY CHILD.

In October 2008 it was determined that the first trial initiative with the 9 "Models for Improvement" hospitals was to increase direct scheduling of outpatient re-screening and/or diagnostic audiology prior to hospital discharge and to submit this electronically in the appropriate fields on the online Hearing Screen Report. Additionally, each regional coordinator has worked with their pilot hospitals to encourage validation and submission of each newborn's medical home/primary care physician. During the pilot hospital's annual site visits, scripts and talking materials were distributed and discussed. Hospitals were asked to implement the use of these materials into their hearing screening protocols. Plan to determine loss to follow-up rate for first half of 2009 and compare to loss to follow-up for last half of 2009 to see if use of scripts have decreased those infants not receiving follow-up.

For the hospitals that are entering the follow up appointment on the hearing screening report at the time of submission, the EHDI follow up coordinator has continued to enter outcomes for those appointments and September 1, 2008 to September 1, 2009 has requested 157 follow up reports from the initial 9 pilot hospitals and received 147 or 94%. For the non-pilot hospitals, she requested 609 reports with 530 returned with outcomes or 87%. In situations where the outcome report indicates a missed appointment, she attempts to contact the family and the medical home. If this is unsuccessful, she notifies the EHDI regional coordinator.

<u>West Region Pilot Hospital Update</u>: During the pilot hospital's annual site visits, scripts and talking materials were distributed and discussed. Hospitals were asked to implement the use of these materials into their hearing screening protocols. Plan to determine loss to follow-up rate for first half of 2009 and compare to loss to follow-up for last half of 2009 to see if use of scripts have decreased those infants not receiving follow-up. Two of the three pilot hospitals currently schedule outpatient rescreens (T.J. Samson and Muhlenburg Community Hospital). The date and time of the follow-up appointment is entered into KY Child prior to infant's discharge from the hospital, facilitating the ability for the EHDI follow-up coordinator to call parents and remind them of the appointment. This also allows the Follow-up Coordinator to request by fax back results of the outpatient screen. If the family does not show for the appointment, the hospitals are attempting to contact the family either by phone or by letter. The infant's primary care physician is informed of the missed appointment. The other pilot hospital (Jennie Stuart) is currently facilitating a follow-up appointment with a diagnostic provider approximately 80% of the time. If the infant is discharged after hours or on a weekend, a referral form is faxed to the diagnostic provider who then contacts the family. Reminder calls for appointments are made from the diagnostic provider's office.

<u>East Region Pilot Hospital Update</u>: Outpatient hearing screens are not routinely conducted for newborns that refer on the hearing screen by the three East Region Pilot Hospitals or the two Central region hospitals. Follow-up appointments that are electronically reported can be tracked

by Kentucky Early Hearing Detection and Intervention. In 2009 the staff at Clark Regional Medical Center implemented as part of their protocol the scheduling of follow-up appointments for infants who refer on newborn hearing screen and discharged on a week day Monday through Friday. In 2008, of the refers 41.7% had a follow-up appointment reported to Early Hearing Detection and Intervention. In 2009 a push has been made for staff to record the appointment on the electronic Hearing Screen Record in KY Child. For newborns discharged on the weekend the pediatrician offices schedules the follow-up appointments. Clark RMC has recently started implementation of scripts and talking points that were distributed to the pilot hospitals.

Hazard Appalachian Regional Hospital includes in their written protocols that an appointment will be made with a designated Audiology Clinic for infants who refer on their newborn hearing screen. Most appointments are made with a local ENT office that has an audiologist. The appointments are recorded on the electronic Hearing Screen Report. In 2008, 81.8% of newborns who referred had a follow-up appointment reported to Early Hearing Detection and Intervention. Follow-up results are faxed by the ENT office to Early Hearing Detection and Intervention. The nurse manager for the Nursery and Neonatal Intensive Care Unit has begun implementation of the scripts and talking points and will be giving an in-service on them to the nurses.

Saint Joseph East Hospital has added to their written protocols that an appointment will be made with a designated Audiology Clinic for infants who refer on their newborn hearing screen. In 2008, 60.3% of newborns who referred had a follow-up appointment reported to Early Hearing Detection and Intervention. More consistency in reporting the follow-up appointments electronically on the Hearing Screen Report form has been encouraged. Copies of scripts and talking points regarding newborn hearing screen have been given to the nurse manager for use by nursing staff.

Central Region Hospitals: Following the departure of Eric Cahill, Central EHDI Regional Coordinator, staffing issues required division of his pilot hospitals among available staff so only two of the pilot hospitals had site visits to date. The addition of Michelle King in the Central-East Regional Coordinator position will fill that gap and St. Elizabeth Medical Center is scheduled for a hospital site visit in November 2009.

At Ephraim McDowell-Fort Logan Hospital most newborns that refer on the newborn hearing screen are scheduled with an audiologist or the parents are given a preprinted list of audiologists per written hospital written protocol. In 2008, 33.3% of newborns who referred had a follow-up appointment reported to Early Hearing Detection and Intervention. More consistency in reporting the follow-up appointments electronically on the Hearing Screen Report form has been encouraged. Copies of scripts and talking points regarding newborn hearing screen have been given to the nurse manager for use by nursing staff and their implementation encouraged.

Lake Cumberland Regional Hospital notifies the pediatrician of the newborns who refer on the screen. Outpatient screens are conducted in the pediatrician's office. If at that time the newborn refers, then the pediatrician refers to an audiology diagnostic site. Follow-up appointments have not been consistently recorded in KY Child on the Hearing Screen Record. Follow-up outpatient results have been received by Early Hearing Detection and Intervention from the pediatric practice. In 2008, 62% of newborns who referred had a follow-up appointment reported to Early

Hearing Detection and Intervention. Consistency in reporting the follow-up appointments electronically on the Hearing Screen Report form has been encouraged. Copies of scripts and talking points regarding newborn hearing screen have been given to the nurse manager for use by nursing staff and their implementation encouraged.

Data from April 1, 2008- March 31, 2009 indicate a total of 9941 live births in the pilot hospitals. Of the total live births 67% had a medical home/primary care physician submitted on the hearing screen report (HSR) to the EHDI database. Of the total 653(7%) referred on the newborn hearing screening and 325 (50%) had a medical home submitted on the HSR. Of the newborns that referred 18% had a follow up appointment submitted electronically while another 44% had follow up appointments entered in the EHDI database by the follow up coordinator as reports were received by fax or mail from the follow up providers.

Current grant year statistics indicate a total of 4322 live births in pilot hospitals with 2905 (67%) submitting medical home information electronically. Of the births 214 (5%) referred in one or both ears on the newborn hearing screening. Of that number 155 (72%) had medical home information submitted electronically. This is significant improvement indicator especially when data from St. Elizabeth's with 57 refers and 0 medical homes submitted is included in the statistical analysis. Of the newborns that referred 63% had a follow up appointment submitted on the HSR with another 22% being entered by the EHDI follow up coordinator on receipt of follow up reports from providers. (See Attachment)

In late 2008 and early 2009 CCSHCN Title V offices across the state began to experience auditory brainstem response (ABR) and otoacoustic emission (OAE) equipment malfunction. In the first year of the grant project ABR and OAE equipment were replaced in the Owensboro office. Additionally, hearing aid analyzers/real ear equipment was no longer usable for the rapidly advancing digital hearing aids. All of the current equipment was purchased through grants and Tobacco Settlement funds prior to 2001. The manufacturers sent letters stating that service and support could no longer be provided with the exception of disposable probes and external parts. The combination of dysfunctional equipment and lack of manufacturer support threatened the pediatric audiologic diagnostic infrastructure that demanded action.

The CCSHCN regional offices in 12 locations across the state are the primary, often sole, provider of infant hearing diagnostics and audiologic intervention, so in many areas this represented a potential crisis of pediatric audiologic assessment as we work to reduce "loss to follow up". A survey of pediatric audiologic diagnostic and intervention equipment was conducted and a plan for replacement through this project was developed based on 1) condition of current equipment 2) number of EHDI referrals 3) type of hospital screening equipment 4) accessibility to audiology diagnostics 5) number of ABRs, OAEs, pediatric hearing aid patients referred to CCSHCN office 6) average socioeconomic level in service area.

With this information, ABR equipment was requested for 4 offices (Paducah, Ashland, Hazard and Louisville) and hearing aid analyzer/real ear for 4 offices (Ashland, Bowling Green, Owensboro, and Paducah) in the current project year. At the present time those requests for purchase have been reviewed in Frankfort and have been submitted for bids. The year 3 budget request for equipment follows the guidelines above.

To continue to remove this obstacle to provision of audiology follow up services for newborns that refer on the newborn hearing screening, in year 3 of the grant equipment request includes ABR diagnostic units for Title V CCSHCN offices in Barbourville, Lexington and Elizabethtown.

The ABR unit is requested for the Barbourville CCSHCN office would replace one of the units. The Barbourville CCSHCN office serves eight counties in the southern Appalachian region of Kentucky and is one of only two sources of pediatric audiology services in that region. Of the 5 UNHS hospitals in the Barbourville area, all use automated auditory brainstem response screening equipment requiring an ABR in the pediatric audiologic evaluation battery for infants that refer on the newborn hearing screening. Although one other source of pediatric audiologic follow up is available in the region, the CCSHCN program provides EHDI follow up diagnostic evaluation at no charge to the family until diagnosis has been confirmed—up to 3 visits precluding significant hardship for families in that economically deprived area. Reducing travel distance and cost for families will decrease the potential that many of these infants could be lost to follow up.

The Lexington CCSHCN office provides auditory brainstem response evaluations for residents of the second largest metropolitan area in Kentucky and for many Northern Kentucky residents as well. Although there are other sources for infant audiologic evaluations with ABR in the Lexington area, again the CCSHCN audiologists provide Early Hearing Detection and Intervention diagnostic follow up at no cost to the families, removing a barrier to follow up that is especially significant in this urban area. The number of infant audiologic diagnostics with ABR provided in the CCSHCN office ranges from 1-4 per week with referrals currently being received from hospitals in Lexington, Northern Kentucky and in the surrounding counties. The age of the equipment and the lack of maintenance support make replacement of this equipment vital since the population served potentially would be lost to follow up if the CCSHCN office could not provide ABR evaluations.

The Elizabethtown CCSHCN office provides infant auditory brainstem evaluation in the Lincoln Trail Health District, which serves 7 counties in Central Kentucky. Within that region there are 5 birthing hospitals, 3 which provide AABR screenings and 2 which provide otoacoustic emission (OAE) screening. One of these hospitals is Ireland Army Hospital at Ft. Knox, KY. Ireland refers infants who do not pass UNHS to Ireland's audiology department and they only see Army dependents. However, the Elizabethtown CCSHCN office is the secondary referral site when an ABR cannot be scheduled within the EHDI guidelines. While the ABR equipment is still functional at this point, the number of births (approximately 3000 annually for the 5 hospitals), the lack of manufacturer support in case of malfunction, and the large geographic area involved, support the need for up-to-date ABR diagnostic equipment

Additionally, Otoacoustic Emission (OAE) diagnostic equipment is requested for the Title V CCSHCN offices located in Bowling Green and Hazard. At the present time the Hazard office has been sharing OAE equipment with the EHDI Regional Coordinator and a site dedicated unit is needed as audiology services are anticipated to expand with the addition of permanent full time audiology staff in 2010. The Hazard CCSHCN office serves eight counties in the Appalachian region of Kentucky and is the sole source of pediatric audiology services in that

region. Bowling Green CCSHCN is also the sole source for pediatric services in the Barren River Health District region of Kentucky with 4 birthing hospitals referring newborns for diagnostic evaluations. The OAE equipment in that office is 10 years old.

To close the follow up gap at the intervention stage with regard to audiologic management, additional equipment requested during year 3 of this project includes hearing aid analysis and verification units**.** These are to be placed in CCSHCN Title V offices at Ashland, Hazard and Elizabethtown, KY. This equipment will be used by direct service audiologists in the provision of services to infants for those infants diagnosed with permanent hearing loss and in need of habilitative audiologic services that include the selection, fitting and verification of personal amplification devices (hearing aid analysis and verification units). Current equipment in these areas that service the east, central and western portions of the state are considered obsolete as direct service providers at these offices are not able to provide audiologic services at nationally accepted standards of care at this time.

With the supplemental grant award received in September 2009, the project added an intentional piece designed to provide non-biased, culturally sensitive support to newly identified infants' families. The concept for extending the project to include a family support plan originated in the original grant proposal and focused on developing a predictable, accountable infrastructure statewide to support families with "next steps" following a referral from newborn hearing screening prior to hospital discharge.

This project includes the CCSHCN parent consultants who are partially funded by HRSA Family to Family (F2F) Grant. The F2F project establishes family centers in Title V offices across the state providing resources and recruiting experienced families of children with special health care needs to work with less experienced families. The inclusion into the "loss to follow up" project includes specific EHDI training for the parent consultants, including 1 parent consultant's attendance with an EHDI regional coordinator at the Investing in Family Support Conference, Scottsdale, AZ and a specific Kentucky EHDI training, these parent consultants will work with the EHDI regional coordinators, Kentucky Hands and Voices Chapter and Kentucky Commission for Deaf and Hard of Hearing to support, coordinate and track families throughout Kentucky as the families navigate through early hearing detection and intervention system. A meeting with Hands and Voices Executive Council is scheduled on November 20, 2009.

The supplemental grant award also opened the door to direct support to Kentucky Hands and Voices for the specific task of developing and maintaining "Guide by Your Side" (GBYS). A meeting on September 18, 2009 with the President and Secretary/Treasurer of Hands and Voices resulted in a projected date of May 2010 for GBYS training. They were charged with providing a plan of action for implementing GBYS and budget for use of the funds allotted through this project by October 30th. The documentation was received and is being reviewed by CCSHCN EHDI project director and fiscal administration.

The EHDDI project goal is rapid reduction of "loss to follow up". The baseline established in the original grant proposal was based on 2006 data documented and received by the EHDI state database. Hospitals in Kentucky, as a condition of continued licensure are mandated to conduct UNHS (Universal Newborn Hearing Screening) and report screening results to the Commission.

"Loss to follow up" in Kentucky is defined by the lack of information received at the EHDI database on infants that referred following UNHS. The infants born in 2006 "lost to follow-up" were: 1) between hospital and outpatient screening were: 1053 of 2193 or 48%; 2) between outpatient screening and audiologic diagnosis: 15 of 1053 or 1% and 3) between diagnosis and entry into early intervention: 11 of 31 or 42%. Of the total number of infants that referred for follow-up at the time of discharge, 1871 of 2,193 or 85% had a medical home identified on the Hearing Screen Report.

For the purpose of this report data was requested from the EHDI database for the grant period April 1, 2008 to March 31, 2009. The infants born in this period that are currently "lost to follow-up" were: 1) between hospital and outpatient screenings were: 760 of 2438 or 31%; 2) between outpatient screening and audiologic diagnosis: 52 of 760 or 7% and 3) between diagnosis and entry into early intervention: 30 of 48 or 63%. Of the total number of infants that referred for follow-up at the time of discharge, 1947 of 2438 or 80% had a medical home identified on the Hearing Screen Report.

Additionally, data was requested for the period of April 1, 2009 to August 31, 2009. During that period there were of 23070 births. "Loss to follow up" in Kentucky is defined by the lack of information received at the EHDI database on infants that referred following UNHS. The number of infants born in this period that are currently "lost to follow-up" were: 1) between hospital and outpatient screening was: 326 of 903 or 36%; 2) between outpatient screening and audiologic diagnosis: 6 of 326 or 2% and 3) between diagnosis and entry into early intervention: 4 of 10 or 40%. Of the total number of infants that referred for follow-up at the time of discharge, 781 of 913 or 86% had a medical home identified on the Hearing Screen Report.

These statistics indicate that the number of newborns lost to follow up between hospital and outpatient testing has been reduced while there has been no significant change between outpatient screening and audiologic diagnosis and an increase between diagnosis and intervention for the April 1, 2008 and March 31, 2009 period. This further supports the plan to use available family consultants and step up collaboration with our partners across the state.

The 2009 EHDI Advisory Board will meet on December 10, 2010 in Louisville, KY. At that meeting status of the EHDI program will be presented as well as current planning strategies for the Advisory Board's guidance and direction.

STAFFING: The project is staffed by members of the Audiology-EHDI Branch at the Commission for Children with Special Health Care Needs. The Project Director is N. Carolyn Kisler, M.A., CCC-A, Audiology-EHDI Branch Manager and Kentucky's Early Hearing Detection and Intervention Program Coordinator. Additional staff in the agency's Audiology-EHDI Branch working on the current project include EHDI Regional Coordinators LouAnn Jones, MS CCC-A, and Kelly Daniel, MS CCC-A, Michelle King, AuD, CCC-A, the Health Program Administrator for EHDI Karen Mercer, RN, BSN, Data Analyst Robert "Scott" Bailey, EHDI Follow-Up Coordinator Karen Holmes, Debbie Gilbert, Parent Consultant and Sondra Gilbert, Parent Consultant.

Since implementation of Universal Newborn Hearing Screening in January 2001, the EHDI staff above has regularly provided technical assistance to birthing hospitals. This included the development and implementation of a Hospital Compliance Manual and an evaluation tool, used to assist hospitals in assessing competencies within their hospital-based newborn hearing screening programs on an annual basis. EHDI staff members communicate regularly with families, diagnostic audiologists, and other health care providers. They have participated in state and national taskforces to improve outcomes for EHDI. In June 2009, it was announced that Eric Cahill, 2008-2009 Project Director had accepted another EHDI position out of state. Carolyn Kisler accepted the responsibility for the grant project. Eric's position as EHDI Regional Coordinator was filled October 1, 2009 when Michelle King, former EHDI Branch Manager rejoined the program as Regional Coordinator. (See Attachments 1 and 2)

Additionally, all Title V CCSHCN audiologists began in January 2009 to assist the Regional Coordinators with hospital site evaluations and technical support as well as providing audiology diagnostics for infants who refer on the newborn hearing screening. This has increased the EHDI programs ability to reach out to local hospital newborn hearing screening programs, local diagnostic audiologists, and the parents of children referring on their newborn hearing screening. Though without specific assignment to work on the current project, this emerging of programs with its associated increase of staff with particular expertise in pediatric audiology has contributed to the overall objectives of the current project. Their relationships with the birthing hospital UNHS programs and the supplemental grant award received for this project in September 2009 permits expansion of the initiatives begun with 9 pilot hospitals to the 47 remaining UNHS hospitals in Kentucky.

In September 2009 CCSHCN administration reviewed the contractual agreements for the EHDI Follow-Up Coordinator position and the Parent Consultant positions. Documentation has been submitted to Kentucky's Personnel Cabinet to approve Karen Holmes, EHDI Follow-Up Coordinator, Debbie Gilbert and Sondra Gilbert, part time EHDI Parent Consultants as federally funded time limited (FFTL) CCSHCN staff. However, at this time that approval has not been received so these three individuals remain contract staff for the purpose of this grant continuance document.

All other staff members at present were in position at the time of the original project proposal. Karen Mercer, RN continues as the EHDI Health Program Administrator with supervisory responsibility over Robert Scott Bailey, data analyst, and Karen Holmes, EHDI Follow-Up Coordinator. Michelle King, East-Central Regional Coordinator, and Kelly Daniel, West Regional Coordinator supervise CCSHCN EHDI audiologists in the, West, and East-Central Regions of Kentucky. Lou Ann Jones, Regional Coordinator at large, supervises contract audiologists who provide EHDI follow up in CCSHCN Title V offices throughout the state. Carolyn Kisler, Audiology-EHDI Branch Manager supervises the state EHDI program, audiology services and the AuD Externship program for CCSHCN. Each team member has specific responsibilities related to this grant project which integrates with Kentucky's multifaceted EHDI program.

<u>TECHNICAL ASSISTANCE NEEDS:</u> The EHDI program would welcome any technical assistance deemed appropriate by the granting authority. It would be useful to have regular

communication with similar programs via list serve or teleconference to share ideas and strategies that have proven useful. Additionally, the EHDI Program would find it useful to have access with specific examples of initiatives developed previously which it is understood serve as the basis for the current project.

LINKAGES ESTABLISHED: Prior to and throughout the project period, the EHDI Program has sought to establish collaborative links with stakeholders in Kentucky. The EHDI Program is currently in collaborative projects with the following entities in Kentucky:

First Steps (Part C): The EHDI Program is currently in discussion with First Steps to develop a Memorandum of Understanding to share information and allow for First Steps providers to report on progress of children previously identified with hearing impairment via the EHDI Programs Computer Utilization Project (CUP). This has been delayed by change in staff and programming at First Steps.

Kentucky Commission on Deaf and Hard of Hearing (KCDHH): KCDHH worked with CCSHCN in the development and passage of House Bill 5. Additionally, the legislation links KCDHH to EHDI requiring them to provide resource packets for the families of every child identified with a hearing loss for the EHDI program to distribute. The KCDHH Executive Director serves on the EHDI Advisory Board meeting in July, 2008.

Hands and Voices of Kentucky: LouAnn Jones, MA CCC-A, Regional EHDI Coordinator represents EHDI on the Executive Board of Hands and Voices of Kentucky developing a collaborative relationship between this vital parent support network and the EHDI Program. Hands and Voices of Kentucky representatives serve on the EHDI Advisory Board. As a part of this collaboration and the state plan undertaken at the National EHDI conference in Dallas, TX, a decision was made to request with the supplemental funding available and awarded in the summer of 2009, funding to assist in implementation of the "Guide by Your Side" (GBYS) program. This program has success in other states reducing loss to follow up due to lack of family support and difficulty navigating the system.

SUMMARY: Willingness to collaborate from all partners is a necessity required to meet the goals of this project of reducing loss to follow-up after failing to pass a newborn hearing screening. The Kentucky EHDI team continues to work toward improving direct referrals prior to hospital discharge and efforts to improve service infrastructure through equipment updates for availability of diagnostic physiologic equipment to allow for completion of appropriate test protocols with audiology service providers for the birth to 6 month population. Improving contact with families and among specialists will forge a more seamless system for parents navigating a foreign process from screening to diagnosis and learning about early intervention strategies. Accomplishment of this has been enhanced by the follow up coordinator and the success of the "fax back" procedure. Enhancement of the state EHDI database (CUP) by adding parameters detailing dates of services, referral and enrollment into various services continues as a part of this project work plan. Ongoing monitoring at each critical juncture: newborn hearing screening prior to discharge; between referral following a failure to pass newborn hearing screening to diagnostic audiology and from obtaining a diagnosis of Deaf or Hard of Hearing and enrollment into early intervention are critical not only to this project but to overall EHDI success.

Kentucky continues to work to reduce loss to follow up by: 1) Streamlining the follow-up process for infants referring after Universal Newborn Hearing Screening to diagnostic audiology services and communication to the medical home by replicating the "models of improvement" in pilot hospitals to statewide birthing hospitals; 2) Improving the seamless follow-up for infants receiving diagnostic audiology services and documented communication to the medical home and EHDI state database following their failure to pass their physiologic Universal Newborn Hearing Screening prior to hospital discharge; 3) equipping CCSHCN offices across the state with pediatric audiologists and diagnostic and intervention equipment, so services are accessible for all families 4) Increasing the documentation of referral to and enrollment into Early Intervention services prior to 6 months of age for infants diagnosed as Deaf or Hard of Hearing; and 5) Continue to improve statewide knowledge, acceptance and support for those infants and young children identified as Deaf or Hard of Hearing and their families through partnerships with the Parent Support Network and collaboration of outreach with members of the EHDI Advisory Board.