Introduction

The primary purpose of this grant application is to request supplemental funding that will enable Indiana's EHDI program to substantially decrease Loss to Follow-up/Documentation (LTF/D) of babies and children throughout the state. The value of early identification of hearing loss has been known for several decades. Since the onset of Universal Newborn Hearing Screening (UNHS) programs, numerous children have demonstrated the benefits of early identification of hearing loss. Knowledge of a child's hearing status allows parents and others the opportunity to intervene in that child's development in a manner that can lead to eventual age-appropriate language skills and successful transition into school. Improvements in hearing screening and diagnostic technology as well as amplification systems allow for children with hearing loss to be identified at just few days of age and to be amplified just weeks later.

Indiana's Hearing Detection and Intervention (EHDI) program was mandated by law in July 1999. The program has worked diligently since that time to improve its hearing screening and follow-up program outcomes. The primary focus of the program is to screen all babies born in Indiana and to decrease the LTF/D at each stage of the EHDI process in order identify babies with hearing loss at the earliest possible time. The program is located in the Department of Genomics and Newborn Screening in the Division of Maternal and Child Health of the Indiana State Department of Health (ISDH). The EHDI program is supported by full-time and part-time staff at ISDH and a network of part-time audiology consultants dispersed regionally across the state. In addition to the strong and diverse EHDI staff (to be discussed in "Organization Information") additional team members include the Director of Genomics and Newborn Screening, the EHDI

Alert Response System (EARS) Information Technology (IT) Consultant and the Maternal & Child Health Epidemiologist. Issues of discussion include data management, EHDI protocols, and project status on a number of ongoing projects related to EHDI, Newborn Screening and the Division of Maternal and Child Health are discussed once monthly in a team meeting attended by these professionals. The Regional Audiology Consultant network also participates in monthly meetings (by conference call or in a day-long face-to-face meeting.) In addition to providing technical assistance and continuing education to hospitals in their respective regions, each Regional Consultant is engaged in an ongoing project to further the work of EHDI. The EHDI program also hosts quarterly meetings of the EHDI Advisory Committee, which consists of a diverse group of thirteen stakeholders. This committee works to assist staff in identifying program gaps, offering solutions for addressing gaps, and creating new ideas and direction for the EHDI program based on feedback and data (outcomes information).

EHDI program staff is involved in many efforts that occur outside of the central (ISDH) office. EHDI recently completed activities which included: 1) statewide training of Part C (First Steps) Early Intervention Intake and Service Coordinators on EHDI protocols and implementation of the newly developed EHDI-First Steps Help Kit; 2) participation (by video conference) in the national State Leaders Summit, an annual meeting that addresses the educational needs of children birth to twenty-one; 3) planning meetings to update Indiana's Family Resource Guide for Deaf and Hard of Hearing Children and; 4) pre-implementation activities related to Indiana's Guide By Your Side (GBYS) program, which will assist EHDI in providing short-term follow-up services to families of identified children beginning September 2009. Also at the state level, EHDI staff is involved in the Early Childhood Comprehensive Services initiative, the Community Integrated System of Services Program (CISS) and the State Deaf Education Task Force. EHDI staff meets quarterly with the state's Director of First Steps (Part C) to discuss issues related to ongoing collaborative work. Currently, EHDI and Part C are working together on several activities including: 1) a pilot project that involves audiologist involvement at Individualized Family Service Plan (IFSP) meetings; 2) efforts to change requirements for enrollment of audiologists as a First Steps Provider, as well as increase the number of audiologists who are First Steps Providers; 3) reimbursement for audiologists who are providing services to babies; and 4) consistent sharing of child-centric data with EHDI.

EHDI has developed a web-based tool to enhance screening and early identification of hearing loss; the program just completed its transition to the second version of its EHDI Alert Response System (EARS). The primary purpose of this surveillance system is to track individual children at all stages of the EHDI process (screening to intervention). The EARS interactive web-based data management system allows for facilitation of early identification, early intervention and reduction of the number of children who are lost to follow-up or documentation. Use of EARS enables hospitals and audiologists to quickly and accurately enter information directly into an EHDI data store. The receipt of this data generates an EARS Alert that notifies EHDI program staff of an individual child's need for follow-up and the recommended action step(s) in the child's case. Eighty percent of Indiana's birthing facilities have participated in training on EARS for the purpose of communicating screening results, recommendations and referrals to ISDH. Personnel from the remaining 20% of birthing facilities provide monthly data via paper which is then entered into EARS by EHDI support staff. These remaining facilities will have another opportunity to receive training in July and August, 2009. Web-based trainings for audiologists serving babies and children will begin in July 2009, with plans to offer five training dates for classes of twenty audiologists per training by October 2009. Indiana's mandate for reporting newborn hearing screening results to ISDH does not specify the vehicle for reporting (i.e. electronic, mail, fax), therefore it is not a requirement that hospitals and audiologists to report babies using EARS. This voluntary use of EARS by hospital personnel and audiologists (once trained) is anticipated to have a dramatic impact on EHDI's knowledge of children who: 1)have not yet been screened; 2) who have been screened and did not pass; 3) who passed the screening, but have risk factors; and 4) who have been identified with hearing loss. Ongoing knowledge of each child and his/her screening and diagnostic status through EARS reporting will allow EHDI staff to conduct actions with families, hospital personnel, primary care physicians, and audiologists that will encourage follow-up (and decrease LTF/D).

The remainder of this narrative provides detailed information about the current strengths, needs, plans and support that Indiana's EHDI program currently has and will need to substantially decrease loss to follow-up/documentation.

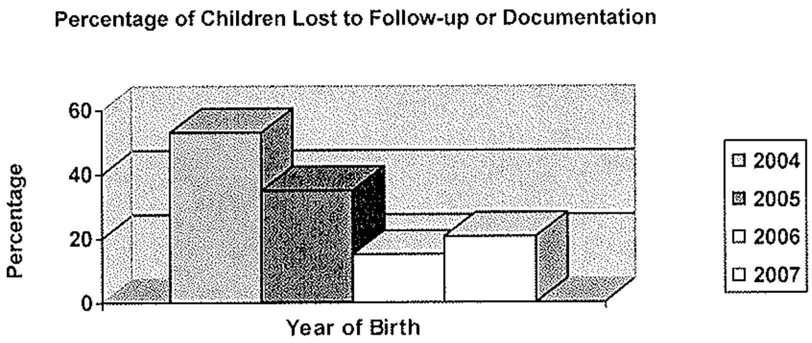
Needs Assessment

The number of occurrent births in Indiana, in 2007, was 89,403 and occurred primarily in the 103 birthing facilities in the state. Of this number of babies, 86% were non-hispanic white, 11% black, and 9% hispanic. There were approximately 1,264 babies who were born at home. Indiana's overall referral rate was 2.7%. Individual hospital referral rates in 2007 ranged from 0% to 9.4%.

Extraordinary progress has made in providing hearing screening to babies since UNHS results were first reported. In 1993, approximately 3% of newborn babies born in the United States received a hearing screening. According to the National Summary of Centers for Disease Control and Prevention (CDC) 2007 data, 94% of babies born in the United States were screened. Of those babies screened, 44.8% did not receive recommended audiological evaluation and were reported as "Lost to Follow-up/Documentation (LTF/D). Of those babies who did not pass, 6.3% were reported to have hearing loss and 64.3% were subsequently enrolled in early intervention services. Conversely, 29.4% of babies with hearing loss were reported as LTF/D.

For the Annual CDC Survey, Indiana reported that 98.1% of the babies born in the state are screened. Of those babies screened, 20.9% did not receive recommended audiological evaluation and were reported as LTF/D. Of those babies who did not pass UNHS, 7.6% were determined to have permanent hearing loss. Of those babies with hearing loss, 71% were enrolled in Part C (First Steps Early Intervention System) services. An additional 8% were known to Part C, but declined Part C services to seek private early intervention services. Conversely, 21% of children identified with hearing loss were unknown to the Part C system and deemed to be LTF/D.

Unfortunately, not all children have access to the opportunities of early identification and early intervention. Indiana's success in providing audiologic follow-up to babies and receiving documentation for that follow-up has been realized only in recent years. The percentage of children lost to follow-up/documentation improved from 54% LTF/D in 2004 to 20.9 % LTF/D in 2007.



While Indiana's 2007 statistics reflect increased success in Early Hearing Detection and Intervention, the program staff and other EHDI stakeholders are committed to ensuring that all appropriate babies are screened, identified, known to the system and receiving early intervention services (as appropriate). It is feasible for the current LTF/D rate to be decreased from 20.9 % for loss to follow-up/documentation from the stage of screening to audiologic diagnosis to less than 10% by December 2010. With some changes to the current processes, it is also feasible that the current LTF/D rate be decreased from 21% from the stage of diagnosis to entry into an early intervention program to less than 5% by July 2011.

Strengths of the Program: Strengths of Indiana's EHDI program include: 1) a highly qualified, diverse staff; 2) a robust web-based data management reporting and surveillance system (EARS); 3) clearly defined screening protocols which includes conducting the second screening of babies who do not pass prior to hospital discharge and; 4) dramatic improvement in LTF/D rates in recent years (2004=54%, 2005=35%, 2006=15%, 2007=20%) from the point of screening to the diagnostic audiology evaluation, 5) addition of the Guide By Your Side (GBYS) Program and Program Coordinator to conduct short-term follow-up activities with families of newly diagnosed children; 6) the relatively new positions of EHDI Follow-up Coordinator and EHDI Parent Consultant in increasing follow-up activities with physicians, audiologists, Part C personnel and parents; 7) participation in the current NICHQ learning collaborative, which is providing our EHDI program with a structured model for testing and instituting change; and 8) the network of EHDI Regional Audiology Consultants who work well with EHDI central office staff and stakeholders in their respective regions. The EHDI program also benefits from a good reputation in the state professional community, strong support from ISDH Administration, and many opportunities to work with others entities concerned about the welfare of young children with special healthcare needs .

Indiana's EHDI program is currently participating in a Learning Collaborative sponsored by the National Initiative on Children's Health Care Quality (NICHQ) (March, 2009-January 2010) which is being funded by the Health Services and Resources Agency (HRSA). The primary focus of this NICHQ Learning Collaborative is to improve access to care for children with special healthcare needs. The seven states who have been invited to participate are focusing on EHDI or epilepsy. Through NICHQ's guidance, a team of 13 professionals has been recruited which includes a parent of a child with permanent hearing loss, a neonatologist, a geneticist, two pediatric audiologists, a pediatrician who services as a primary care provider (PCP), a data expert, the EHDI Coordinator, the EHDI Follow-up Coordinator, the Maternal and Children's Special Health Care Medical Director, the Director of Maternal and Children, and the Manager of Community Integrated System of Services Program (CISS).

The Indiana NICHQ Team has established an Aim Statement which supports the EHDI 1-3-6 goals (screening by one month, diagnosis before three months and intervention by six months). In addition, the group has established a number of goals to be achieved by March 2010. The goals include 1) increase the accuracy of primary care provider (PCP) to 95%, 2) increase the percentage of babies receiving diagnostic audiology before three months of age to 75%, 3) reduce the length of time children wait for initial diagnostic audiology appointments to seven days or less, 4) increase the percentage of children fit with amplification within one month of diagnosis to 50%, 5) increase the percentage of children with IFSP by six months of age to 50%, and 6) increase the percentage of families who receive support through parent-to-parent support and a written care plan to 75%.

This highly motivated, energetic group has examined the EHDI process at one of the largest birthing facilities in Indiana that also has a large NICU and has identified strengths of the system and several opportunities for improvement. Baseline data has been collected and pilot projects affecting different points in the EHDI process are underway.

<u>Needs of the Program:</u> Indiana's EHDI program has undergone significant change in the past two years, primarily due to developing and strengthening EHDI staff and program support, introduction of a web-based data management system (EARS), increased contact with hospital UNHS program personnel, and recent involvement in the NICHQ learning collaborative. Indiana has program needs within each stage of the EHDI process that, if ameliorated or met, could immediately reduce Indiana's LTF/D: Current program needs

are addressed below within the areas of 1) universal newborn hearing screening at birthing facilities, 2) referral from screening to diagnostic audiology services, and 3) referral from diagnosis to early intervention and family support.

Universal Newborn Hearing Screening at Birthing Facilities:

Data collected for the annual CDC Survey on babies born in 2007 indicated that 98.1% of Indiana babies were screened. The 1.9% of babies who were not screened were comprised of children whose parents signed a religious waiver, who left the hospital before they could be screened and whose parents declined to return (known as "unauthorized refusal"), and those babies who were born by home birth and whose parents declined screening (known as "unauthorized refusal").

In effort to create increased public, and particularly, parental awareness of hearing and EHDI, (and therefore, the likelihood that more babies will be screened, receive appropriate follow-up, and monitored in early childhood for hearing loss), EHDI would like to provide information to local health departments and other places parents visit. EHDI plans to provide materials (and where agreeable, parents who can give a two-minute "elevator speech") in places of dependably high new parent traffic (i.e. Pre-Natal Classes, Women, Infant and Children's [WIC] Clinics and Immunization Clinics). EHDI will also seek to place information in the offices of primary care physicians and other Medical Homes.

EHDI staff had the opportunity to conduct ten, one-time EARS training with hospital screening program personnel during the past year. Feedback from participants (representative of 80% of Indiana birthing hospitals) indicated that this training provided: a) sufficient technical assistance in learning to use the EARS database for reporting to

ISDH; b) helped to solidify the importance of their integral role on the EHDI team in decreasing loss to follow-up/documentation; and c) demonstrated the impact that screening and early identification has on babies and families. In an evaluation of each training, the majority of participants, when queried about which aspect of the training would have the most impact on their future use of EARS, the majority indicated that "the story" as told by the parent (of a child with hearing loss) who assisted with a portion of the training, made the importance of their job and use of EARS "real". This feedback was so compelling that EHDI plans to develop a quarterly electronic newsletter ("The EHDI-Gram") as a continual motivation for hospitals and other EHDI stakeholders to recognize the importance of their role in reducing LTF/D. "The EHDI-Gram" will offer information, news, and spotlights on programs, professionals, parents, babies and kids related to EHDI.

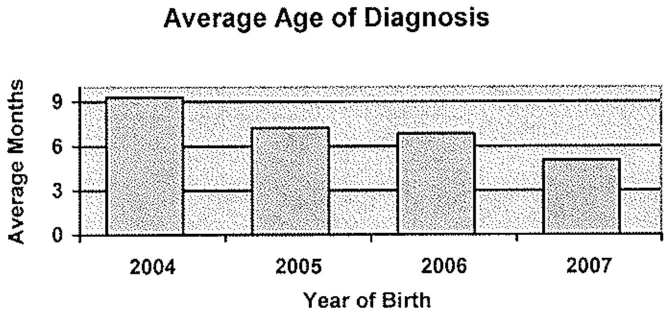
The state's overall referral rate of 2.7 % (1.9% for babies who did not pass UNHS; 0.8 % for babies who passed UNHS, but had risk factors) for babies born in 2007 was well within the referral rate recommended by the Joint Committee on Infant Hearing (JCIH) in its 2007 Position Statement. However, in a recent assessment of 2007 individual hospital referral rates, it was found that nearly 50% of Indiana hospitals have a low (<1%) or high (>4%) screening refer rate. Facilities with Neonatal Intensive Care Units (NICU) generally report higher referral rates, although this has not been of significant concern considering the number of babies with high risk birth conditions in the birth and transfer population of these facilities. Still, the exceptional referral rate of so many facilities is of concern and warrants immediate attention.

Each birthing facility in the state is assigned to a Regional Audiology Consultant. The Regional Audiologists have been required to make one face-to-face annual (through a regional hospital training or site visit) contact with each facility in their region to provide continuing education and to provide feedback and technical assistance to the UNHS program. The Regional Consultants also are available as needed for phone calls, email communication, and (additional) hospital site visits. Because there are many factors that can affect a hospitals referral rate (i.e. equipment function, staff knowledge and training or lack of thereof) and because of the high number of facilities with exceptional referral rates), EHDI would like to increase the hours of the EHDI Follow-up Coordinator for the purpose of increasing data reports and assistance to the Regional Audiology Consultants who will begin to make quarterly contact with their hospitals to discuss results from quarterly data reports, an evaluation of the cause of any exceptional findings and possible solutions that will assist that facility with their referral and other rates (i.e. # of babies screened, # of babies who receive follow-up).

EHDI program staff updated its hospital equipment list in April 2009. All 103 Indiana birthing facilities have facility-owned hearing screening equipment, however, 15 hospitals are without Auditory Brainstem Response (ABR) screening equipment and 5 hospitals were listed to be using the Sonomed Clarity screener (which has been declared to be appropriate as a screening tool only when an audiologist is available for interpretation of findings). To gain additional information, EHDI sent an email survey to hospital screening program contacts in June, 2009 to learn the present condition/functionality of current equipment and any perceived need for replacement equipment. Approximately one-third of Indiana hospitals responded that they are interested in pursuing updated equipment for their facility. Of those respondents, about one-fourth indicated that the cost to replace equipment in their facilities is prohibitive during these economic times. Equipment condition/functionality will be given attention by the Regional EHDI Audiology Consultant Network at each visit, recognizing that malfunctioning and older equipment may account for the high percentage of hospitals (50%) that have exceptional referral rates.

Referral from Screening to Diagnosis:

Data collected for the annual CDC Survey on babies born in 2007 indicated 1.9% of babies screened did not pass two UNHS screenings and were referred for audiologic evaluation. Of those babies who did not pass, 79.1% were documented to receive audiologic follow-up and 20.9% were classified as LTF/D. While the majority of Indiana babies complete the screening process before age one month, there is often a significant time delay for babies to receive audiologic follow-up and confirmation of hearing status. Related, Indiana has not reached the goal of identifying babies before three months of age, yet significant progress has been made. As demonstrated below, the average age of identification has improved from 9.31 months in 2004 to 5.04 months in 2007.



The current average age of first evaluation is three months. Currently, infants who do not pass UNHS or who pass, but have risk factors for late onset hearing loss, are referred by the birthing facility via fax to Indiana's Part C (First Steps Early Intervention) program for follow-up coordination of services and payment for diagnostic testing. The hospital informs the family that First Steps will contact them at home within two days to assist them with scheduling the baby for follow-up. Hospital personnel also provide a hearing screening certificate (which indicates hearing screening results and risk factors), a general brochure about EHDI, and a second brochure if their baby needs additional testing (audiological evaluation). Families are also directed to contact First Steps and/or EHDI should they not receive the expected phone call from First Steps.

Seeking audiologic follow-up through First Steps involves the following process: 1) a visit (usually at the family's home) from a First Steps Intake Coordinator to enroll the child in the program; parent selection of an audiologist from the First Steps Matrix also occurs during this visit; 2) processing of First Steps paperwork (which includes a referral form from the child's physician, data input of enrollment forms, prior authorization from the audiologist, and possible scheduling of the evaluation); 3) authorization paperwork posted to the First Steps website for the audiologist to view; and if not done previously; 4) scheduling of an evaluation appointment with the audiologist. Data regarding the number of families who choose to pursue follow-up through First Steps versus private insurance is not available to EHDI, however, it appears that the majority of families pursue follow-up through First Steps. EHDI does not have access to the date of first contact by First Steps, but the time frame appears to range from 2 days (as per protocol) to two weeks.

In efforts to decrease the amount of time for follow-up to occur, EHDI Program staff piloted making re-referrals to Part C from November, 2008 through February, 2009.

Feedback from First Steps offices revealed that it was difficult for their personnel to respond to the emails in a timely manner with the information requested and that the duplication of referrals was creating additional work. Recognizing the barriers, this protocol was discontinued in February, 2009. Further evaluation of the current referral process has since been conducted through NICHQ and has led to the recommendation that scheduling of audiology appointments by hospital personnel be tested (piloted) at a few hospitals. Also through the NICHQ project and to determine if scheduling of audiologic evaluation appointments can be modified, EHDI is collecting time to third new appointment data. Initially, EHDI staff had planned to pilot this strategy with one First Steps Early Intervention System Point of Entry (SPOE), however, it has since been determined that these calls could be made by EHDI program staff, who are generally more familiar with hearing loss than the typical intake or service coordinator might be (depending on location). Instead, EHDI will be piloting this activity with St. Vincent-Indianapolis and one other Indianapolis birthing facility. Provided the pilot project provides data supports this protocol, two parent consultants (one who is already with EHDI and one bilingual parent) will be employed to provide this intensive follow-up with parents. EHDI will request that hospital personnel provide the Parent Consultant with the appointment date and name of audiologist when they enter this child into the EARS database to ensure that timely follow-up occurs from EHDI. Results of the pilot study will be evaluated to assist the program in determining a model of implementation for the state that will drive the first evaluation appointment wait time from the current average of three months to six weeks of age.

Beyond the scope of the NICHQ project, it is imperative that parents receive appropriate assistance during each stage of the EHDI process. The current EHDI Parent Consultant has primarily been in contact and provides resources and support to families of children diagnosed with hearing loss. With the initiation of Indiana's Guide By Your Side program in September, 2009, families of children identified with hearing loss will receive short-term follow-up primarily through that program. This opportunity will allow the EHDI Parent Consultant to conduct follow-up with many more parents, particularly those who need to seek audiologic follow-up, and those who have children with pending diagnoses. More than 8,000 babies are born to Hispanic families each year. EHDI program staff, with the assistance of a bilingual clerk, is in contact with families, whose first language is Spanish, several times weekly. The program needs to build its capacity to provide appropriate programming for these families, as the need for access to a Spanish-speaking parent consultant and to Spanish materials (beyond EHDI's Spanish brochures) has become apparent. In addition to assisting with the NICHQ pilot project, the bilingual EHDI Parent Consultant will provide assistance to both English and Spanish-speaking families to facilitate the EHDI process. If awarded supplemental funding, EHDI will be able to pursue the additional employment of its current Parent Consultant and pursue the second Parent Consultant.

In addition to the child-centric letters that are sent to primary care physicians to indicate that a child is in need of follow-up and may their need their immediate assistance, EHDI staff would like to send lists to primary care physicians (PCP) of children in their practice that remain "open/pending". The EARS database can be used to generate these reports that may be either faxed or sent by certified email. EHDI would like to employ the current EHDI Follow-up Coordinator for additional hours, with supplemental funds from this grant, should it be awarded, to conduct this more intensive follow-up with PCP and other Medical Home personnel.

A survey of Indiana's audiologists, conducted by the EHDI Program in November, 2008 indicated 63 audiology facilities were providing services to children in Indiana. Of that number, 26 audiology facilities were enrolled as (Part C) First Steps providers. This reflects that only 41% of audiology facilities are providing First Step services. Results of this survey suggested that many audiologists, who could be enrolled as First Steps providers, do not do so because of inadequate reimbursement of services and the amount of paperwork required to enroll and participate in the program. In this survey, 21 audiology facilities reported the ability to conduct comprehensive diagnostic audiology assessment (as recommended by JCIH) of infants and young infants. An additional 6 facilities reported the ability to conduct audiology assessment on infants and young infants, but lacked one piece of equipment (i.e. bone conduction ABR, high frequency tympanometry) to conduct a comprehensive assessment to make a differential diagnosis. An additional 8 facilities expressed interest in providing services to young infants, but indicated a need for support and equipment in order to do so successfully. If supplemental funds are awarded to Indiana's EHDI program, a loaner equipment program will be set up through the EHDI program for Year One and audiology practices will be able to complete an application for use of equipment;

EHDI staff recognizes that the dedication and hard work of professionals involved in EHDI should be acknowledged. In addition to the quarterly electronic newsletter being created for hospital personnel, a separate quarterly "EHDI-Gram" will be developed for audiologists. In addition to providing new information regarding EHDI audiology protocols, the newsletter will be used to spotlight programs and professionals, to heighten awareness of the importance of EHDI and the work being done by individuals across the state, and to serve as a networking. This tool can also be used as a venue for Part C to make announcements, share information, and to invite audiologist to become new First Steps providers.

Referral from Diagnosis to Early Intervention and Family Support:

Data collected for the annual CDC Survey on babies born in 2007 indicated of those babies who were diagnosed with permanent hearing loss, 71% were enrolled in Part C (First Steps Early Intervention System) services. An additional 8% were known to Part C, but declined Part C services to seek private early intervention services. Conversely, 21% of children identified with hearing loss were unknown to the Part C system and deemed to be LTF/D from the stage of diagnosis to early intervention.

One primary reason for early identification is to lessen the impact of hearing loss on a child's development. Indiana's EHDI program has been invited to participate in the National Early Childhood Assessment Project (NECAP) long-term outcomes project currently in process under the direction of Dr. Christine Yoshinaga-Itano at the University of Colorado-Boulder. Through involvement in this project, families of identified children would be given the option to participate in a study that looks at progress in communication development from the point of diagnosis to age four. The study employs the use of parent-report assessment tools (the *Minnesota Child Development Inventory* and the *MacArthur Communication Developmental Inventory*) at designated intervals. Parents complete each assessment and mail the results to the

University of Colorado. The results are analyzed and interpreted and a report is sent to the parents (with a copy to the Indiana EHDI program) of their child's results and progress in communication development since the last test administration.

If supplemental funds are awarded to Indiana's EHDI program, NECAP interpretation of the baseline and annual assessments of individual children identified through EHDI will be funded by ISDH. The Guide By Your Side parent guides will provide the initial assessment forms at one of the six visits EHDI is funding (through HRSA). A script will be developed for guides to use when providing the forms. The script will impart the importance of pursuing early intervention services at the earliest feasible time and the necessity of evaluating a child's communication over time, so parents and professionals are able to maximize a child's communication development and capitalize on any opportunities to develop age-level communication skills prior to enrollment in Part B services at age three. An annual report of aggregate results of the performance of Indiana's children will be shared with Indiana's Part C program and EHDI program staff at HRSA. These results will also be used as one metric to evaluate the EHDI program's impact as a result of early identification of hearing loss.

Related to IFSP development and the impact of EHDI on the intervention process and communication development in children with hearing loss, EHDI is set to conduct a 3-month pilot project with Part C (First Steps) in approximately twenty counties in the southwestern portion of the state. Two EHDI Regional Audiology Consultants will participate in IFSP meetings for children residing in these counties either in person, by phone, or by sending specific recommendations for goals/objectives and services to a child's Part C Intake Coordinator prior to the meeting. These regional consultants have extensive experience in participating in the IFSP process and represent a small number of audiologists who regularly attend IFSP meetings of their clients in the state. Both consultant's have anecdotally observed that children in their practice (outside of their work with EHDI) appear to be able to move through the identification and intervention processes, receive authorization for services and receive appropriate services earlier than children located in other portions of the state. This project is being conducted to assess the benefits and impact of an audiologist's involvement in the IFSP process, both in the short term and over time. Self-assessments (completed by the two EHDI Regional Audiology Consultants), and a parent assessment and intake coordinator assessment will be completed at the conclusion of each IFSP meeting and mailed to ISDH. Data will be interpreted during and at the conclusion of the project to formulate recommendations to Part C regarding the importance of audiologist involvement in the IFSP process. Results will also be used in developing resources for Indiana audiologists to use to maximize the impact of their involvement in the development of Individualized Family Service Plans (IFSP), whether attending meetings in person, by phone or by sending recommendations in advance of the meeting. Families who complete the survey will receive a follow-up survey one year later to seek their feedback on the impact (if any) of having an audiologist involved in the development of their child's IFSP the preceding year.

Babies born in 2007 who were diagnosed with unilateral or minimal to mild hearing loss represented 38.5% of the total number of children diagnosed. This data suggests a need to provide a degree of separate programming and materials for these babies and families. EHDI will develop two separate Parent Toolkits to meet the needs of these families of babies and children with unilateral, minimal and mild hearing losses.

EHDI will also assist families in seeking appropriate intervention services and assess additional opportunities that may be available to ensure that these families are not lost to follow-up or documentation.

Methodology

EHDI has utilized the SMART technique for writing goals and objectives to address program needs for improvement; that is, all goals and objectives were written to be **S**pecific, **M**easurable, **A**chievable, **R**ealistic, and **T**ime-framed. While use of SMART is a widely accepted method for the creation of goals and objectives, SMART does not address how to determine priorities, manage those priorities, effective measurement strategies or when to make "course corrections." Consequently, the EHDI program has added the Model of Improvement to its methodologies for addressing program needs, priorities, outcomes and evaluation. The three fundamental questions of the Model of Improvement (What are we trying to accomplish? How will we know that a change is an improvement? What change can we make that will result in improvement?), and the Plan,-Do-Study-Act (PDSA) cycle of the Model will be used to achieve the goals, objectives, and outcomes indicated on Indiana's Work Plan. Because of space limitations regarding this application the narrative and attached Indiana EHDI Work Plan are focused on to the additional objectives and activities described within this application. Refer to the original Indiana Work Plan grant #H61MC00059 a detailed description of the foundational goals, objectives, and activities for the project. The goals out lined in the original HRSA grant application for the Indiana EHDI Program continue. The additional objectives, measures and activities developed for this supplemental grant application will more aggressively address the lost to follow-up issues related to 1) universal newborn hearing screening at birthing facilities, 2) referral from screening to diagnostic audiology services, 3) referral from diagnosis to early intervention and family support which were discussed previously in the Needs Assessment. The measures, objectives and activities which have been included are discussed in the following pages, and the area (1) universal newborn hearing screening at birthing facilities, 2) referral from screening to diagnostic audiology services, 3) referral from diagnosis to early intervention and family support) which will be affected are also listed in the remainder of this methodology section.

Goal 2 (as indicated on the Work Plan): To achieve the Healthy People 2010 goal 28.11 (also known as "1-3-6"), the Indiana EHDI program staff, birthing facilities, audiologists, and physicians will report children who do not pass UNHS and those with risk factors associated with delayed onset of hearing loss, those who have received a diagnostic hearing evaluation, and those who have been identified with hearing loss to ISDH. Nine additional objectives have been added in this supplemental grant application and are as follows:

New Measures: The proportion of UNHS programs outside of the targeted range of referral (less than 1% and greater than 4%) will be reduced from 50% to 25% by 2011. Additionally, the average age of first evaluation will be decreased from three months to six weeks of age by 2011, and 75% of babies diagnosed with hearing loss will participate in the National Early Childhood Assessment Program (NECAP) long-term follow-up program by 2011. There are a number of new objectives added to Goal 2 for this supplemental grant. They include the following:

New Objective: 85% of Indiana babies who do not pass UNHS will receive a diagnostic audiologic evaluation before three months of age by June 2011. *This targets the area from referral from screening to diagnostic audiology services.*

New Activities/Methods: Indiana EHDI staff will work with the NICHQ Learning Collaborative to modify referral processes to reduce the age at first evaluation from 3 months to six weeks of age. Indiana EHDI staff will work with the NICHQ Learning Collaborative to collect time to third new appointment data to determine if scheduling of patients can be modified to reduce the wait time to 14 days or less. Indiana EHDI will identify methods of spreading improved methods of scheduling evaluations throughout the state.

New Objective: The EHDI program will assist three to five hospitals annually with replacement of screening equipment that may no longer be effective at providing accurate results. *This additional objective addresses the area of universal newborn hearing screening at birthing facilities*

New Activity/Method: The EHDI program will enable birthing facilities to apply for grant funds to be used to purchase replacement equipment.

New Objective: The EHDI program will improve the quality of feedback to hospital UNHS programs to enhance referral and loss to follow-up/documentation by providing technical support and written reports at least quarterly by June 2011. *This again targets the area of universal newborn hearing screening at birthing facilities.*

New Activities/Methods include: Facilities with screening rates outside the targeted referral range of 1-4% will be identified. Facilities identified will be provided with additional training to facilitate appropriate screening rates.

Regional Consultants will consult with hospitals quarterly. EHDI staff will provide to each hospital screening rates twice per year. The EHDI staff will improve education of nursing staff for both week and weekend staff by implementing live and static web-based trainings. The EHDI staff will determine and share referral rates and determine if certain days or periods of the month reveal larger referral rates.

New Objective: The EHDI Program will provide increased assistance to families in accessing hearing screening and audiological care to enhance the likelihood that timely follow-up occurs with babies who did not pass UNHS or who passed, but have risk factors for late onset hearing loss by contacting families, physicians or early intervention if no follow-up data is received by six weeks of age by June 2011. *This objective targets two areas including universal newborn hearing screening at birthing facilities and referral from screening to diagnostic audiology services*

New Activities/Methods include: that the EHDI Follow-up Coordinator will contact families, physicians and First Steps Early Intervention to obtain follow-up data and to assist with scheduling of follow-up testing if none has occurred. The EHDI Parent Consultants, one of whom will be bilingual, will contact families to assist with scheduling of recommended follow-up services including diagnostic audiology evaluations and referral to early intervention as needed.

New Objective: By June 2011 the EHDI Program will provide increased communication with the medical home by sending letters and calling medical homes of 80% of children who continue to have "open/pending" status to ensure that follow-up evaluations are completed as soon as possible. *This objective targets the area from referral from screening to diagnostic audiology services*

New Activities/Methods: The EHDI Program will create EARS reports that produce a list of babies who are "open/pending" associated with a given medical home or Primary Care Provider (PCP). The EHDI Program will fax or email (through secured email) lists on a bi-monthly basis to medical homes/PCPs assigned to children in need of follow-up.

New objective: By June 2011 the EHDI Program will at a minimum communicate with professionals and parents quarterly to acknowledge outstanding work of professionals, parents and others involved in the EHDI process. *This targets the areas from universal newborn hearing screening at birthing facilities, referral from screening to diagnostic audiology services, and referral from diagnosis to early intervention and family support*

New Activity/Method: An EHDI-gram highlighting professionals, facilities, and/or parents exhibiting excellence in the area of EHDI will be sent via email on a quarterly basis.

New Objective: By June 2011, the EHDI staff will increase the number of audiology providers providing diagnostic services to young babies and children by 20%. *The targeted area is referral from screening to diagnostic audiology services*

New Activity/Method: The EHDI program will enable audiologists and audiology practices to apply for grant funds to be used to purchase replacement equipment.

New Objective: By June 2010, the EHDI program will provide Spanish support and materials to 90% of Spanish speaking families contacting the EHDI program. *Referral from screening to diagnostic audiology services is this objective's target area.*

New Activities/Methods: The EHDI Program will hire and train a part-time, Bi-lingual Parent Consultant to assist with EHDI follow-up. The EHDI program will add a Spanish message to the voicemail of all EHDI staff members. The EHDI Program will add a language preference to the Diagnostic Audiology Evaluation form and to the EHDI Long-term Follow-up (ELF) form in EARS to improve follow-up with families.

New Objective: By January 2010, the EHDI Program will begin participation in the National Early Childhood Assessment Project (NECAP) by recruiting at a minimum 75% of children diagnosed with permanent hearing loss who live in Indiana to evaluate the long-term impact of EHDI. *The area addressed by this objective is referral from diagnosis to early intervention and family support*

New Activities/Methods: The EHDI Program will develop procedures to effectively participate in the NECAP long-term outcomes study. The EHDI Program will use the data from NECAP to analyze trends within Indiana related to development of children with permanent hearing loss.

Goal 5 (as indicated on the Work Plan): To provide an integrated, system of support to parents of children identified with hearing loss to assist in achieving positive communication, social, educational and adjustment outcomes for the child and family through the EHDI Program and Indiana Hands & Voices. Three new objectives have been added to Goal 5 for this supplemental grant request. The objectives are described as follows:

New Objective: By June 2011, the EHDI Program will heighten awareness and knowledge of EHDI during periods of time when new parents are most sensitive and attentive to information about their babies by adding EHDI materials to prenatal education information provided at a minimum 25% of Indiana birthing facilities. *This objective affects the area of universal newborn hearing screening at birthing facilities.*

> **New Activities/Methods:** The EHDI Program and Indiana NICHQ Team will identify Prenatal Education Coordinators at each birthing facility. The EHDI Program and the Indiana NICHQ Team will pilot and then spread successful methods of including EHDI materials into prenatal education resources for mothers.

New Objective: By June 2011, the EHDI Program will increase the knowledge of families about the importance of early and periodic hearing screening and any needed follow-up to ensure that more babies are screened and to decrease the number of babies who are lost to follow-up/documentation by providing outreach activities to PCPs, medical home providers, and county health department WIC and immunization staff a minimum of one location monthly. *This targets the area of universal newborn hearing* screening at birthing facilities.

> **New Activities/Methods a)** The EHDI Program will identify the appropriate contacts in the above mentioned facilities to begin providing outreach efforts. The EHDI Program will develop a presentation and determine appropriate resources to be shared during outreach activities The EHDI Program will provide outreach

activities to medical homes, Primary Care Providers, state and local WIC staff, county health department staff, and state and local immunizations staff.

New Objective: The EHDI Program will standardize the educational materials provided to families of children with unilateral, minimal, or mild hearing loss. *This objective affects the area from referral from diagnosis to early intervention and family support.*

New Activity/Method: The EHDI Program will standardize the educational materials provided to families of children with unilateral, minimal, or mild hearing loss.

Work Plan

The 2009-2011 Work Plan indicates objectives, activities, data to be evaluated, timeframes for assessing progress, team members responsible, and overall measures of success for the following goals1) to reduce the number of infants and families that are lost to follow-up, the EHDI program will increase the follow-up of parents on behalf of their children from the initial point of entry (Universal Newborn Hearing Screening); 2) to achieve the Healthy People 2010 goal 28.11 (also known as "1-3-6"), the Indiana EHDI program staff, birthing facilities, audiologists, and physicians will report children who do not pass UNHS or who passed with risk factors, who have received a diagnostic hearing evaluation, and who have been identified with hearing loss to ISDH; 3) to collaborate with the First Steps Early Intervention Program and other state agencies with implementing methods to build capacity in skilled providers who work with deaf and hard of hearing children and their families and encourage new and continued enrollment in the First Steps Early Intervention System; 4) to expand awareness and education among professionals about EHDI goals, objectives and resources; and 5) to provide an integrated, system support to parents of children identified with hearing loss to assist in achieving positive communication, social, educational and adjustment outcomes for the child and family.

New objectives, tied to this supplemental grant application, are included on the Supplemental Work Plan. Goals and objectives listed on the attached Supplemental Work Plan will be evaluated for quantitative and qualitative progress at six-month intervals. Bi-weekly staff meetings of EHDI staff will be held and quarterly meetings will be completed with clerical staff and data entry personnel to review procedures and address any concerns or questions that arise related to program and database operations. This Supplemental Work Plan will also be shared with the EHDI Advisory Committee who will assist the state in meeting its goals and objectives by providing feedback regarding progress and suggestions for "course corrections" should the EHDI data indicate the need for change.

Resolution of Challenges

The EHDI program has made significant strides in addressing loss to follow-up, however, two significant barriers to full implementation of EHDI are present. The first barrier is that e*arly, timely, consistent and appropriate follow-up services for children and families are not yet a reality for many of our Indiana families.* Mandated Universal Newborn Hearing Screening and follow-up and the participation and leadership of the EHDI staff in the community, while important, are not sufficient in the creation of meaningful systems change in Indiana. Statewide use of our EARS data management system by audiologists and hospital personnel in communicating results to the EHDI program and targeted, intensive attention to reducing loss to follow-up at each point (screening through intervention) in the EHDI process, as outlined in the Methodology section, should decrease Indiana's loss to follow-up/documentation from birth to screening, from screening to confirmation of hearing status, and from diagnosis to intervention. To facilitate the completion of the new objectives outlined on the Work Plan, EHDI is seeking funding support for additional hours for the EHDI Follow-up Consultant. The Follow-up Consultant, an audiologist by training, will work with internal staff to assist in retrieving and interpreting data from the EARS system and will assist the EHDI Parent Consultants with issues related to follow-up. Externally, the EHDI Follow-up Coordinator will provide support to audiologists, physicians, and Part C personnel participating in EHDI.

Additionally, Indiana's use of Guide By Your Side parent guides should significantly impact that age that babies receive amplification, engage in family support activities and organizations, and enroll in early intervention services. The importance of parent to parent support has been demonstrated by research studies with results indicating that parents who receive parent to parent support show significant improvements in 1) the acceptance of their child's disability, 2) the ability to cope with the additional needs of the child, 3) the ability to obtain the services needed for their child, and 4) the knowledge that there are other families with similar circumstances who can assist the family in their journey (Singer, G.H.S., Marquis, J., Powers, L.K., Blanchard, L., DiVenere, N. Santelli, B., (1999) and Ainbinder, J.G., Blanchard, L.W., Singer, G.H., Sullivan, M.E., Powers, L.K., Marquis, J.G., & Santelli, B. (1998)). With this in mind, EHDI is seeking support from the Health Resources and Services Agency (HRSA) to employ the current EHDI Parent Consultant for ten additional hours and to employee a new bilingual EHDI Parent

Consultant for twenty hours to provide assistance to families from the point of referral for audiological follow-up to the point of families' (with children identified with hearing loss) voluntary involvement in the GBYS program. Because Guide By Your Side is currently focused on families of identified children, the work of the EHDI Parent Consultants will primarily be focused on communicating with parents following referral from screening and prior to and following audiological evaluation and confirmation of hearing status. Those families who decline GBYS services will continue to have access to an EHDI Parent Consultant, who will share the EHDI Parent Toolkit and document services being provided to those families.

The second barrier to full implementation of EHDI is *the verification of diagnostic audiologic evaluation results, enrollment in First Steps (Part C) and provision of early intervention services for children diagnosed with hearing loss.* EHDI staff and the Part C Director of the First Steps Early Intervention system meet quarterly to discuss data sharing, follow-up issues and solutions for improving services within both agencies. The Part C Director has indicated that she is working towards an electronic solution for the sharing of child-centric data. The Part C Director recognizes that the EHDI Program's role is more than that of Child Find; that in fact, the program is a participating provider of service to children through the follow-up and support services families receive through the EHDI Program. The Part C Director has been agreeable to recommended changes for pre-authorization of audiology services and recognizes that reimbursement and enrollment procedures are barriers to the provision of audiology services to families. The Director has agreed to consider changes in enrollment requirements for audiologists that would substantially decrease the paperwork required to participate. The Part C Director has been very supportive of the integration of the EARS data management system into EHDI service provision and invited EHDI to train staff on the system. Additionally, the Director is supportive of the pilot project that will soon be conducted in the southwestern region of state, in which EHDI Regional Audiology Consultants will assist in development of the Individualized Family Service Plan (IFSP) for newly identified babies. If this project is successful, there may be an opportunity for implementation across the state. EHDI's involvement in the IFSP would allow access to important information about the date of enrollment in intervention and the services secured for children identified through EHDI.

Evaluation and Technical Support Capacity

Program evaluation has been ongoing since the inception of the UNHS program in Indiana in 1999. Data collection for the purposes of analyzing program performance and setting new priorities and future direction has been gathered primarily using questionnaires, surveys and analysis of UNHS data items available through the EHDI program's Access-based UNHS database. Basic data items, such as the number of babies screened before one month of age, the mean age at the first audiology evaluation (2.9 months in 2007), and the mean age of confirmed diagnosis (5 months in 2007) are readily available. Data related to outcomes has been much more difficult to obtain and report from the UNHS database.

The EARS data management system was developed to decrease data and reporting issues, as well as, to generate alerts and responses that would decrease the number of children lost to follow-up or documentation. In the design of EARS, attention was given to ensuring that information that is routinely requested on the Annual Centers for Disease Control and Prevention (CDC) Survey would be available through system reports. Recognizing the need for additional support and expertise, an epidemiologist was recently hired to serve the Genomics, Newborn Screening, and EHDI programs. The epidemiologist's expertise, access to Child Health Information Profiles in EARS, and access to the Integrated Data Store (IDS), which is connected to other ISDH systems (i.e. Vital Records information) allows for more targeted queries of our databases. Team meetings that focus on evaluation of this information are currently conducted on a monthly basis. Team members include the Epidemiologist, Director of Genomics and Newborn Screening, Information Technology staff, the EHDI Program Director, and EHDI Follow-up Coordinator. Documentation of data queries and reports are supported by IT staff and the epidemiologist. The EHDI Program Director has obtained graduate degrees in both audiology and speech-language pathology and is also a Certified Auditory-Verbal Therapist. Additionally, she has recent experience working in non-profit program administration for an international organization focused on serving individuals with hearing loss and has extensive experience in program evaluation. The EHDI Follow-up Coordinator is an audiologist and has broad experience in serving children with hearing loss and their families. As the former State Audiology Coordinator, she has an unparalleled depth of knowledge, skills and institutional history. These two EHDI professionals will work together to ensure that data is gathered and reported as indicated on the Work Plan.

The EARS data management system is flexible to the degree that it will allow for the generation of numerous administration and data reports. EHDI staff, Information Technology staff and the epidemiologist will align available reports with those reports needed to describe progress on the objectives listed on the Work Plan. Data on all objectives will be shared in the annual HRSA performance reports. EHDI data will also be reported on the annual CDC performance reports and, if requested, to the National Center for Hearing Assessment and Management (NCHAM). Efforts will be made to disseminate results in at least one publication and at one national conference in order to gather feedback, receive additional evaluation of the program, and provide technical assistance to others. The EHDI Program will seek technical assistance from state and federal resources for the duration of the grant period.

The integrity of data is paramount to the success of the EHDI Program, therefore it is important that several strategies are used to monitor the quality of data entered into the Universal Newborn Hearing Screening (UNHS) database, EARS, and the IDS. Cross-checking of babies identified with hearing loss will be done with the Indiana Birth Defects and Problems and Registry (IBDPR). The IBDPR collects data received by hospitals and physicians related to children from birth to three years of age with diagnosed conditions. Secondly, the accuracy of the UNHS data received by the Indiana University Laboratory (which analyzes and enters information from the heel stick card) for children who do not pass the hearing screening will be evaluated by comparing information to the Monthly Summary Reports entered into EARS by each birthing facility. In addition, each hospital using EARS will receive periodic data audits by EHDI personnel. This information will be shared with respective hospitals twice annually (once as an Annual Report Card.) Hospital trainings will continue to be evaluated at the conclusion of each training session and audiology EARS trainings will be peer-reviewed (by email). A summarized written report will be created at the conclusion of each year.

And finally, the EHDI Advisory Committee will also be asked to complete periodic evaluations of grant activities and will be provided with information about goals and activities not yet completed. The EHDI Advisory Committee will be provided with results of surveys and other data queries in order assist the program in identifying and determining solutions to program gaps. As indicated earlier in this narrative, the EHDI Advisory Committee will be also be provided with the EHDI Work Plan to ensure that they have access to the EHDI goals, objectives, methodologies, strategies and activities that have been developed to decrease loss to follow-up and documentation across the state.

Organizational Information

The mission of the Indiana State Department of Health (ISDH) is to support Indiana's economic prosperity and quality of life by promoting, protecting and providing for the health of Hoosiers in their communities. The Early Hearing Detection and Intervention (EHDI) Program serves the people of Indiana to fulfill this mission and the mission of the EHDI program. Universal Newborn Hearing Screening and follow-up was mandated in 1999 with the following language indicated in Law Indiana Code 16-41-17-2: Section 2: Every infant shall be given a physiological hearing screening examination at the earliest feasible time for detection of a hearing impairment. If a parent of an infant objects in writing, for reasons pertaining to religious beliefs only, the infant is exempt from the examination; Section 3: The state department shall conduct an intensive educational program among physicians, hospitals, public health nurses, and the public concerning the disorder; Section 4: The state department shall require appropriate tests to be used in the detection of disorders; Section 6: The state department shall provide forms on which the results of tests performed on each child for the disorders listed in section 2 of this chapter shall be reported to the state department by physicians and hospitals; Section 9: A registry for tracking and follow-up of all newborns and individuals for screening and a centralized program that provides follow-up, diagnosis, management, and family counseling and support.

A second law, (Indiana Code-16-38-1), passed in October, 2006 in support of the Indiana Birth Defects and Problems Registry (IBDPR) requires that physicians and audiologists report children birth to age three who are diagnosed with any of the 46 selected health conditions (which includes permanent hearing loss). Physician's report to the IBDPR using a Physician's Reporting Form (provided by ISDH) that is faxed to the ISDH and deciphered electronically (this process is changing to online submission in the coming months). Audiologists report to the IBDPR using the Diagnostic Audiology Evaluation (DAE) reporting form (also provided by ISDH) that may be faxed or mailed to ISDH. As indicated previously in this narrative, this form will be submitted electronically by audiologists through the EARS data management system in the near future.

The Indiana State Department of Health (ISDH) has made significant progress in the development of its integrated child health information through the Integrated Data Store (IDS). The IDS currently integrates information received from a number of sources including the Indiana University Newborn Screening Lab, hospital discharge codes, Vital Records, chart auditor codes, UNHS/EHDI Hospital Monthly Summary Reports (through EARS), Diagnostic Audiology Evaluation reports (through EARS in the fall of 2009).

EHDI staff prepared an ambitious Work Plan for the three year period of this HRSA grant in November, 2008. New objectives, tied to this supplemental grant application, are included on the Supplemental Work Plan. Indiana's program has three full-time employees (EHDI Program Director, UNHS Program Director, and one clerical staff), and two part-time employees (the EHDI Follow-up Coordinator, EHDI Parent Consultant) assigned to the program. In addition, nine Regional Audiology Consultants continue to work with the EHDI staff in the six regions of the state on a consultative basis. Additional support comes from other state agencies such as First Steps Early Intervention, Outreach Services for Deaf and Hard of Hearing Children, and the Department of Education. Biographical sketches for staff that work or will be working with the EHDI program through HRSA grant funding are included in this application.

Members of the EHDI Advisory Committee are committed to making EHDI an outstanding program and participate on "working" subcommittees to assist on special projects. In addition to the state and local resources available to Indiana's program, resources from the Centers for Disease Control (CDC), the National Center on Hearing Assessment and Management (NCHAM), Indiana, and also the American Speech-Language-Hearing Association (ASHA), will be available to assist the program by providing models of materials that may be used. Also, Indiana's EHDI Program Director serves as the Region V representative for NCHAM and as the Chair for Division 9 (Childhood Hearing Loss) for ASHA and has accesses to resources through those opportunities.

Indiana's EHDI Program including ISDH staff, consultants, and other stakeholders who contributed to this process appreciate the opportunity to submit this supplemental grant funding application in support of improving "loss to follow-up/documentation" in Indiana.