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A. BACKGROUND AND NEED

1. Background Information: An Overview

The Indiana General Assembly passed the Universal Newborn Hearing Screening (UNHS) Law in May 1999. The law required 1) all infants born in the state of Indiana to be screened for hearing loss at the earliest possible time, 2) results to be reported to the Indiana State Department of Health (ISDH) in a timely manner, and 3) implementation of a system of tracking and follow-up of babies referred from UNHS. Furthermore, the law established the Governor's Newborn Hearing Screening Advisory Board. Although the portion of the law that mandated the Advisory Board sunset in June 2002, an Early Hearing Detection and Intervention (EHDI) Advisory Committee was convened and meets approximately three times annually. The twelve members of the current committee represent a cross-section of EHDI stakeholders including three parent representatives, a Professor of Audiology, an Otologist, a Pediatrician (American Academy of Pediatrics Chapter Champion), First Steps Early Intervention (Part C) Coordinator, the Director of Indiana Outreach Services for Deaf and Hard of Hearing Children (Outreach Services), a Deaf Early Interventionist/Parent, the State EHDI Coordinator (Audiologist/Speech-Language Pathologist), the Director of Genomics and Newborn Screening, and the Medical Director of Maternal and Children's Special Health Care Services at the Indiana State Department of Health.

At the onset of the state's UNHS/EHDI program, six Regional Audiologists were funded (part-time) through a grant awarded to ISDH from the Health and Human Resource Administration (HRSA). Initially, ISDH contracted with Outreach Services (which is located at the Indiana State School for the Deaf (ISD)) to hire and manage the Regional Audiology Consultants. With guidance from the Governor's Newborn Hearing Screening Advisory Board, the Regional Consultants developed protocols for the EHDI program and assisted hospitals across the state in the establishment of UNHS programs. Upon the hire of a full-time EHDI Audiology Coordinator in 2004 by ISDH, the Regional Consultants came under the supervision of the new Coordinator at ISDH (see Additional Information, Organizational Charts, Regional Audiology Consultant-Regional Map). The program is located in the Program of Genomics and Newborn Screening in the Division of Maternal and Child Health. The program continues to be coordinated through a full-time State EHDI Coordinator (title change from EHDI Audiology Coordinator) contracted to ISDH. The Coordinator works directly with other program staff including the UNHS Nurse Consultant (full-time), the EHDI Parent Consultant (Part-time), Lead Regional Consultant (Part-time), eight Regional Consultants (covering six regions of Indiana) and clerical staff for the day-to-day functioning of the program. Each Regional Consultant consults up to 30 hours a month for the EHDI program, as they have other audiology positions outside of the EHDI program (see Additional Information, Curriculum Vitae**).** The Regional Audiology Consultants provide technical assistance and consultation, in addition to in-services for hospital staff, public health nurses, and local First Steps Early Intervention (Part C) providers, audiologists, speech language pathologists and physicians. Recent strategic planning conducted with the Regional Consultants confirmed a collective desire to become more involved with follow-up on individual children, to work on additional special projects, and to participate in leadership activities in their respective regions and at the state level on behalf of EHDI. The Regional Consultant role has moved from the implementation of the UNHS screening program to encompass a broader role in the follow-up and surveillance process of EHDI.

The Director of Genomics and Newborn Screening, the State EHDI Coordinator, the Lead Regional Consultant, UNHS Nurse Consultant, EHDI Parent Consultant and an IT

Consultant meet weekly as a team to discuss issues related to EHDI protocols, data management, training of personnel, and any changes of in plans or timing related to transitioning the EHDI program to a new data management system (see Additional Information, EHDI Protocols, EARS Dataflow Protocols). The past three years have been significant in that the Genomics and Newborn Screening staff has worked extensively with Information Technology staff in the development of the new EHDI Alert Response System (EARS) data management system. EARS is an interactive web-based application that allows hospitals and audiologists (external users) to quickly and accurately enter information directly into a data store. Entered information can be read by EHDI program staff (internal users) almost instantaneously and generates alerts and informs the appropriate staff member of the next follow-up act needed in this child's EHDI process. EARS was developed to replace the Access-based UNHS database that was developed in 2003. This database could not interact with other databases and involved time-consuming, high volume of data entry by staff. Additionally, the database was limited in its ability to generate data and reports. In contrast, EARS is designed to improve tracking, data management and follow-up in the following areas:

- Increased accuracy and reporting by hospitals and audiologists (through direct data entry)
- Reduced paperwork for all users (external and internal) because of direct data entry on to forms previously available only in hard copy
- Increased timeliness of data sharing (immediate access to information by ISDH staff on babies referred from UNHS screening)

- Increased timeliness of follow-up by generation of time-sensitive alerts by the EARS system to users regarding a child's hearing status and next follow-up step(s) to be taken with a particular child
- Improved communication and collaboration with EHDI partners (i.e. secured emails to Part C System Points of Entry (SPOE) supervisors and audiologists providing diagnostic assessments)
- Improved integration of data through interaction with the larger Operational Data Store (ODS) (allowing for vital exchange of information among programs)
- Reduced loss to follow-up and documentation of children because of closer monitoring by EHDI program staff. EARS creates a Child Health Information Profile (CHIP) on each child as soon as a birthing center enters UNHS results on that child and the State EHDI Coordinator or UNHS Consultant is notified of this new child immediately through an alert from the system
- Improved flexibility in the system for other ISDH applications

Current areas of focus in the EHDI program include full implementation of the new EHDI Alert Response System (EARS), improved follow-up with families of children in the EHDI process, collaborative work with other agencies to develop capacity in providers of service, and provision of supports to families concerned with the issues and impact of hearing loss, and work with the EHDI Advisory Committee and other stakeholders on developing new awareness and educational materials and campaigns for professionals and parents in Indiana.

2. UNHS/EHDI – 2006 Statistics

According to our Monthly Summary Report data, 97.8% of babies were screened for hearing loss in Indiana in 2006. Of this number, 1665 babies (1.9%) did not pass newborn hearing screening, yielding the following outcomes: 1215 (75%) exhibited normal hearing at a follow-up diagnostic audiology evaluation; 112 (7%) were confirmed to have a permanent hearing loss; 33 (2%) were still involved in the diagnostic process (without a confirmed diagnosis); 57 (3%) of the parents moved, refused evaluation, or baby passed away; 248 (15%) loss to follow-up/documentation. Of those babies who did not receive a screening, 407 parents refused to do so based on religious objections. Calculations using the EHDI data suggest an incidence of 1.3 children identified with hearing loss per 1,000 live births. In 2006, 112 babies (born that year) were identified with hearing loss through the EHDI process. An additional 47 babies (born before 2006) were identified in 2006 for a total of 159 babies identified with hearing loss in 2006 in Indiana

Most babies received diagnostic testing before age two months, however, the mean age of confirmed diagnosis was 4 months; 20 days for the cohort of babies born in 2006. ISDH would like to be able to confirm the hearing status of approximately 248 children (15%) who were lost to follow-up/documentation. In the past three years, Indiana's calculated percentage for babies lost to follow-up/documentation decreased from 54% for babies born in 2004 to 35% for babies born in 2005 to 15% for babies born in 2006.

ISDH also recognizes the need to improve long-term follow-up care. Currently, ISDH receives documentation on individual babies with hearing loss only up to the point of diagnosis (via the DAE form) and would like to be able to track diagnosed babies through the initial early intervention process. Finally, ISDH /EHDI intends to improve follow-up for babies who passed

UNHS with risk factors by initiating phone calls to those families who, have not followed through with the recommended evaluation by age 12 months. Families of babies who have passed UNHS, but who are at risk for late onset of hearing loss, currently are notified of the need for evaluation by the birthing center, then through First Steps Early Intervention (Part C), and again by letter from the EHDI program.

3. Current Program Gaps and Need:

The UNHS/EHDI program in Indiana has made significant strides within the last three years. The program is committed to address the significant challenges that continue to exist in the following areas:

a. Data Management

The Indiana State Department of Health (ISDH) has been actively working to strengthen the public health information infrastructure in Indiana to address hardware, application, and connectivity issues that affect the Agency's ability to collect, share, and use data and information about the health of Indiana residents. ISDH's vision statement, for developing information systems to facilitate data and information activities is, "An ***easy to use, integrated*** electronic information environment that provides ISDH employees and others with ***immediate access*** to the ***accurate, timely health data*** they need to work more ***effectively*** and ***efficiently."***

The principles of this vision statement guided development of the Access-based UNHS database system that was implemented in December, 2003 and also the development of the web-based EARS database that is currently being implemented. The database tracks aggregate data including: the total number of babies who were screened, the total number of babies who were not screened because of religious objection, the total number of babies who were transferred from one facility to another, the total number of babies who did not pass UNHS, and the total number of babies who were identified as at risk for delayed onset of hearing loss. In addition, the database assisted with tracking and follow-up of each individual child in need of services. The UNHS database improved follow-up by providing easy access to basic demographic information, reason for referral (MSR), and results from the diagnostic audiologic testing (DAE form). Automatic letter generation was also created in late 2004 to enabled timely generation of letters to families whose children were in need of additional testing and the physician following the child.

In January 2001 the development of the Operational Data Store (ODS) began, as a pilot project, as part of the Birth Defects Surveillance System Cooperative Agreement. This data repository was designed to improve the state's accessibility to data by integrating information for Vital Records (including birth, death, and fetal death certificate data), hospital discharge data (HDD), newborn screening (NBS) lab data (from heel sticks), UNHS data, and eventually other data sources that match the data in a person-centric child health data set. The ODS Schema is based on an Oracle 9i platform (Indiana State government standard) and meets Public Health Information Network (PHIN) compliance recommendations. Funds from a previous CDC grant enabled the development and initial implementation of the EHDI (EARS) portion of the ODS. This project, near completion, will need critical attention in the next few years, but most particularly in the next year as Alert-related processes are refined.

Until EARS was developed, all hospitals and audiologists reported information on babies through completion of mailed, emailed or faxed forms. Hospital personnel responsible for hospital UNHS programs completed a lengthy Monthly Summary Report (MSR). During the testing phase of EARS (with four Indianapolis area birthing centers), the paper MSR was shortened to match the MSR data points in the EARS application. Whether reporting by paper or electronic MSR, a primary purpose of the report is to share information on the number of babies born, number of babies screened, and number and names of babies classified as an exception (which includes any baby at the hospital who has not t been screened and babies who receive a result of “did not pass” or “passed, but has risk factors” for late onset hearing loss. The paper and electronic MSR include a summary page for aggregate data, a reason code page for reporting babies who were not screened (i.e. hospital error, death, transfer, NICU, etc.), and a referral code page for reporting babies who did not pass UNHS or have risk factors. The Monthly Summary Report (MSR) is due at ISDH by the 15th of each month for the previous month’s births. Hospitals submitting the MSR (electronically) through EARS are also required to submit the MSR by the 15th of the month, however, many hospitals will submit the MSR at the very beginning of the month so that may begin reporting for the new month. The EARS system only allows for hospital personnel to have access to two months (i.e. March, April) in one period, with a rationale that timeliness of reporting will improve.

Audiologists complete a one-page Diagnostic Audiology Evaluation (DAE) form to report results of evaluation on children who are referred for follow-up from hospital UNHS programs. The paper form of the DAE has been revised to be consistent with the electronic DAE format. The DAE form has been in use for five years and has served well as a voluntary method for audiologists to report ISDH the results of follow-up testing. Most audiologists use this form to also fulfill the requirement that all children identified with hearing loss be reported to the State’s Individuals with Birth Defects and Problems Registry (IBDPR). The EARS electronic DAE is currently being piloted among the Regional Consultants, who work in clinics and evaluate children with hearing loss outside of their EHDI work. Regional trainings on the electronic DAE are anticipated to begin in August 2008. Both the MSR and DAE forms were developed to facilitate an organized method of reporting and tracking children who had not been screened, or who received a “did not pass” or “passed, but with risk factors” final result. Once EARS is fully implemented, it is anticipated that use of the paper forms will decrease significantly.

Transition to a new data management system, the EHDI Alert Response System, has been challenging. Because training of all Indiana birthing facilities and audiologists involved in EHDI is still far from complete, EHDI staff is working out of two databases (the UNHS System and EARS) in order to track and monitor babies from hospitals not yet using EARS and also the eighteen hospitals (4 pilot hospitals and 14 other hospitals) that have been trained on EARS. The EHDI staff is excited about EARS; receiving an Alert on a baby that is just a few days old is a new experience for EHDI staff who generally did not receive any information on babies who were exceptions until they were ages 2 to 6 weeks. EARS gives the EHDI staff the opportunity to contact First Steps Early Intervention, physicians, and families through its Alert Response Center as early as the same day a child’s Alert is received. The Alert Response Center allows for sending secured emails, generation of letters, and recording of phone conversations and faxes.

Four central Indiana hospitals participated in the piloting the EARS MSR (testing) application and were instrumental in preparing EARS to move to its production application on January 1, 2008. Since that time, fourteen additional central Indiana hospitals have participated in one of the three trainings held to date. Trainings have since been opened up to hospital personnel across the state and the next three trainings have a complete roster of participants set to travel to Indianapolis for the day-long training. Addition sessions will be held throughout the year until the majority of hospitals have been trained. Hospital personnel who have already participated in the training have demonstrated excitement and willingness to use the new system.

Each training group is limited to 8 to10 participants to ensure a good staff-to-learner ratio, individualized attention by the Lead Trainer, and plenty of hands-on practice with EARS. Evaluations have been good to excellent. A summary of participant evaluations for all trainings will be provided in the next CDC Performance Report. ISDH's goal is that all hospitals in Indiana interested in using the system will have the opportunity to be trained prior to the end of the calendar year (December, 2008). It is anticipated that the majority of hospitals will use EARS, but that some hospitals will choose to continue to report on paper via fax, mail, or email. All hospitals are required to participate in an Indianapolis-based training in order to gain access and use of EARS. The Indianapolis training is required to provide a controlled environment as the trainees are using a test environment to enter practice data into the system and to comfortably learn to navigate the system. The EARS Consultant and Regional Consultant will provide phone consultations and site visits to provide additional support as needed.

The Information Technology (IT) Consultant/EARS Application Developer has led each of the three trainings held to date. It is anticipated that the State EHDI Coordinator and the newly hired EARS Consultant will conduct these trainings beginning in June. The IT Consultant's familiarity with EARS and his understanding of IT issues has been invaluable in these trainings, especially in a time in which data migration and changes to the server that hosts EARS have been in progress. The IT Consultant's expertise and understanding of the entire EARS system continues to be essential for improving the application over time. Many issues were identified by the pilot hospitals during the testing phase of data entry into the system and their feedback and the ability of the IT Consultant to find and fix issues prepared a relatively smooth transition from the testing to production application of EARS. Some additional issues have emerged from changes to the server that require the continued daily monitoring and expertise of the IT staff.

Additional gaps and program needs in the area of data management include:

- Collecting information from home births and mid-wife facilities. A contract (which will allow the lending of screening equipment) is in process between ISDH and two large mid-wife facilities. In 2006, approximately 800 home births were reported by the Division of Vital Statistics
- Methods for collecting complete demographic information on the infant, mother and father are in process. Once reports have been developed for the new EARS system, we anticipate greater communication between internal data systems.

b. <u>Tracking and Follow-up</u>

- Acquiring results for “border babies” (babies born in neighboring states) continues to be inconsistent. Two states report with some consistency those children who are residents of Indiana, but born in their state. As indicated in the past, without the knowledge of the status of these babies, there is likely an increased rate of children who are lost to follow-up and a reduction in the accuracy of incidence numbers. Face-to-face visits to all four neighboring states are planned during this grant period to facilitate protocols [and perhaps a Memorandum of Understanding (MOU)] between Indiana and each state on how and what information will be shared regarding these babies.
- Follow-up on babies who have not been screened, who have not kept appointments for follow-up evaluation, who are risk for hearing loss, who are unresponsive to letters from the EHDI program or whose evaluation results, and follow-up reports have not been reported to ISDH continues to be an issue. The hiring of a part-time Parent Consultant (June 2007) has improved follow-up with parents of newly identified children in the past

six months. The hiring of an EHDI Follow-Up Consultant (anticipated start date of September 2008) should also improve follow-up among the above-mentioned groups.

- As mentioned above, ISDH anticipated the transition from the Access database to the EARS system would prove challenging. Some extenuating circumstances have made this transition more difficult than originally expected. Changes to the ISDH Server that hosts the EARS applications, updates to the system, the involved process of training and assisting hospital personnel on reporting through EARS, and working between two databases has complicated the transition. The MSR reporting mechanism is working well and this is important considering that this is the portion of the system accessed and used by external users (hospital personnel). EHDI and IT staff plan are currently working to improve the Alert Response Center, develop EARS reports and are preparing to launch the electronic DAE report from the testing application to production application.

c. Early Intervention

- Sharing of person-centric information between ISDH and First Steps Early Intervention (Part C) continues to be a significant issue, with the restrictions of the Family Education Rights and Privacy Act (FERPA) a primary impediment in data sharing between the two agencies. The State's Part C Coordinator has indicated that her agency will develop a new Reciprocal Release form that includes the EHDI Program as a specifically-named entity. The Part C Coordinator, State EHDI Coordinator and additional ISDH staff meet on a fairly regular basis to discuss current issues and work together to reach better outcomes for children with hearing loss in Indiana.
- The number and capacity of audiologists, speech pathologists, and deaf educators who possess the needed skills to work with infants and toddlers with hearing loss needs to be

increased in order to serve children throughout the state. EHDI does provide opportunities for professionals to build knowledge and skills in diagnosis and intervention with babies and toddlers with hearing loss through in-service trainings...

- Comprehensive information about communication opportunities, amplification, and educational options for children with hearing loss is not as consistently offered or available to new families as needed per parent report. The SKI*HI Curriculum was brought to Indiana three years ago in attempt to address this issue. However, of the 41 individuals trained to be Parent Advisors, only about 15 proceeded to work as Parent Advisors. The rate of reimbursement and lack of travel funds to the family's natural environment has been problematic. EHDI Program staff plan to attend the July 2008 National Hands and Voices Conference in Colorado for training on a parent-to-parent mentoring program, Guide by Your Side. Adoption of this program by the EHDI program (administered through the Indiana Chapter of Hands and Voices) is being strongly considered as another form of support to parents and children in Indiana.

d. Awareness and Education

- Even with increased education and publicity, many Primary Care Physicians continue to be uninformed about the importance of UNHS and EHDI programs, and related issues such as genetic counseling and related services hearing, and efforts to make sure all children have a Medical Home.
- Turn-over of screening staff at birthing centers continues to be high. Program staff is near completion of a new training for both hospital personnel (screeners) and public health nurses.

The program needs, as outlined above, facilitated the development of the following 3-Year Work Plan (See additional documents, Work Plan), which is presented in brief below.

B. WORK PLAN

In order to address areas of concern and to further develop Indiana's EHDI program, the focus of this grant period will be on creating change in the following five goal areas:

1) To enhance data collection and management for the Indiana. Objectives under this goal include:

- 80% of Indiana birthing facilities will use the EHDI Alert Response System (EARS) data management system in effort to improve documentation methods and program statistics for at least 80% of all data points included in the Annual CDC Survey by June 2011.
- 80% of Indiana audiologists who work with children will submit Diagnostic Audiology Report (DAE) results either by EARS or by hard copy by June 2010.
- EARS Data Reports will be created and implemented by September 2008.

2) To achieve the American Academy of Pediatrics (AAP) 1-3-6 Plan, the Indiana EHDI Program staff, Birthing Facilities, audiologists, and physicians will report children in need of services to the ISDH (EHDI or Indiana Birth Defects and Problems Registry (IBDPR). Objectives under this goal include:

- 98.5% of Indiana babies will receive Universal Newborn Hearing Screening (UNHS) before one month of age by June 2011.
- 85% of Indiana babies not passing UNHS will receive a diagnostic audiologic evaluation before three months of age.

- At least 75% of babies with confirmed hearing loss will be enrolled in early intervention by six months of age by June 2011.
- Protocols will be created and implemented to improve follow-up for babies from neighboring states by June 2011.

3) To collaborate with 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. Objectives under this goal include:

- The EHDI program will involve at least 60% of providers of early intervention services in ongoing awareness and educational activities provided through the program by the end of the grant period (June 2011).
- The EHDI program will co-host no less than one conference/workshop per year for Early Intervention professionals (audiologists, speech-language pathologists, educators, psychologists, etc.).

4) To expand awareness and education among professionals about EHDI goals, objectives and resources. Objectives under this goal include:

- The EHDI Program will develop Physician Outreach materials to share current information about components of EHDI, Medical Home, and the 2007 JCIH Position Statement for implementation across the State by December 2010.
- 80% of the 106 birthing facility MSR contacts will receive one annual face-to-face contact from the EHDI program by 2011.
- 80% of local Health Department personnel will participate in one regional face-to-face activity per year by 2011.

5) To expand awareness and education among parents about EHDI goals, objectives and resources. Objectives under this goal include:

- 95% of families with babies with documented hearing loss through EHDI will be sent resource information from the EHDI Program by 2011.
- 95% of families of babies with documented hearing loss through EHDI will be sent information about family support organizations no later than one month post diagnosis as measured through EARS reports.
- 95% of families of babies with a confirmed hearing loss will be contacted by the EHDI program within two weeks of confirmation of diagnosis (by letter) and within four weeks of confirmation of diagnosis (by phone) by June 2011.
- The EHDI Program will develop a written 3-year plan with the Indiana chapter of Hands and Voices by November 2008 regarding their (H+V) long-term role in family support on behalf of the EHDI Program.
- The EHDI Program will work with a representative group of stakeholders (which should include at least 4 parents and 4 professionals) to complete a new edition of Indiana's Family Resource Guide.
- The EHDI Program will translate all parent materials into Spanish by December 2010.

While much of the work in these areas will be lead by ISDH and its staff and consultants, most goals areas will depend on collaboration among stakeholders such as hospital personnel and audiologists across the state providing direct EHDI services, First Steps Early Intervention (Part C), Outreach Services, Family Support Organizations physicians and parents of children with hearing loss, and the EHDI Advisory Committee.

C. COLLABORATIVE EFFORTS

The Indiana State Department of Health continues to demonstrate a strong commitment to the EHDI mission and program and supports EHDI as a program in the Genomics and Newborn Screening Department in the division of Maternal & Children’s Special Health Care Services. The EHDI program has been successful in its development because of the collaborative efforts of many agencies including the state’s 106 birthing centers, First Steps Early Intervention (Part C), Outreach Services, the Indiana Perinatal Network, the Indiana Chapter of Hands and Voices, and the EHDI Advisory Committee.

The Universal Newborn Hearing Screening Advisory Board that was established in 1999 created an immediate connection between the Indiana State Department of Health (ISDH) and professionals around the state. As the program has continued to develop, the relationship with the First Steps Early Intervention (Part C) has strengthened. While we still do not receive person-centric information, First Steps Early Intervention has been supportive of EHDI efforts and aggregate data on children with hearing loss receiving early intervention services has been shared when requested. In addition, First Steps continues to invite EHDI participation in trainings and our Regional Audiology Consultants typically provide at least one Audiology forum and several regional trainings annually to increase knowledge and skills for providers other best practices for diagnosis and intervention with deaf and hard of hearing children.

As stated in the Indiana law PL91-1999, all hospitals were mandated to be in compliance with UNHS by July, 2000. The Regional Audiology Consultants, the UNHS Nurse Consultant, and State EHDI Coordinator have an ongoing collaborative relationship with the 106 birthing centers in the state. Hospitals are contacted on a regular basis to clarify data received or to track babies in need of additional services. Hospitals provide monthly documentation in the form of a

Monthly Summary Report (MSR) on children to the EHDI program. The EARS database does allow for secured email communication between EHDI, hospital personnel, and First Steps Early Intervention nine cluster offices across the state. It is anticipated that communication between hospital personnel, First Steps Early Intervention and EHDI staff will become even more regular and efficient.

Physician education and collaboration will receive greater emphasis over the next several years. The State EHDI Coordinator, Regional Audiology Consultants, American Academy of Pediatrics Chapter Champion, the Indiana Perinatal Network (IPN) and other ISDH representatives will look for and capitalize on collaborative opportunities with state organizations including: the Indiana Chapter of the American Academy of Pediatrics, the Indiana Rural Health Association, the Indiana Public Health Association, the Indiana Chapter of Family Practice, the Indiana Head Start Association and other such organizations. The EHDI program will target these organizations by submitting articles to newsletters, exhibiting or presenting at conferences, and providing education and guidance to the Indiana University School of Medicine’s residency programs. The Indiana Perinatal Network (IPN) works with EHDI by providing opportunities for collaboration in exhibiting at conferences/trainings and supportive work on State initiatives and campaigns (i.e. Medial Home Initiative). The EHDI program is just beginning to experience the opportunities that EARS provides in communicating with physicians so quickly after the baby’s birth and anticipate that physicians will contact EHDI regularly for information.

The Genomics and Newborn Screening Program is committed to linking children with metabolic conditions and hearing loss to a medical home and is currently involved with the Region IV Genetics Collaborative funded through HRSA. This effort is providing additional support to our own department through the opportunities it provides to interact with other state departments in which EHDI and Newborn Screening our housed together.

As ISDH continues to refine the Operational Data Store (ODS), which is an integrated system combining newborn screening heel stick data, vital statistics, and hospital discharge birth defects data, collaborative work with the Indiana University Newborn Screening Lab (IU lab) will continue. The IU Lab processes all newborn heel stick screens completed in Indiana and enters the UNHS results into their data management system, Specimen Gate. The blood spot card contains improved data fields including: mother's middle initial, mother's date of birth, improved race and ethnicity categories, improved infant status categories (premature, normal, transfused, etc.), and includes UNHS information (date of screen, ear specific results, the presence or absence risk factors, and reasons for screening not completed). Use of Specimen Gate provides the results for all births and allows for accuracy checks for both databases currently used by EHDI.

On a larger perspective, the EHDI program will continue to collaborate with the National Center for Hearing Assessment and Management, the Directors of Speech and Hearing Programs in State Health and Welfare Agencies, and the U.S. Department of Health and Human Services' Health Resources and Services Administration and the Centers for Disease Control by providing requested data, participating in teleconferences, and attending national conferences related to reaching EHDI and Healthy People 2010's overall goals.

ISDH has partnered and contracted (through a grant award received from the Health Resources and Services Agency (HRSA) with the Indiana Chapter of Hands and Voices to implement several activities that may foster family support for EHDI families. Hands and Voices, a non-profit, parent-led organization, is designed to support deaf and hard of hearing children and their families across communication modalities. EHDI has partnered with Hands and Voices to increase EHDI's support of families through a variety of education and networking opportunities. A Hands and Voices committee of parents and one professional (working in support role) has planned and will implement the 5th Annual EHDI Family Conference in July 2008. The conference serves as the kick-off activity for a series of other activities that are designed to build capacity for family support. It will provide an opportunity for families to create a one-to three year family plan while at the conference with the support from a trained Parent Advocate. Additional activities include regional family support meetings that will provide continued contact opportunities for families who met one another at the Family Conference. The regional meetings will be designed in a way that will also allow families to feel welcomed and encouraged by follow-up discussions and activities. In addition, three topical conference calls [which will be accessed by parents who are deaf or hard of hearing through ISDH's provision of Captioned Real-time Translation (CART)] will be co-hosted by ISDH and the Indiana Chapter of Hands and Voices in fall, 2008. This will allow families to participate, right from their homes, in a facilitated discussion with speakers from the conference. In support of Hands and Voices' and its role as a family support organization, EHDI will work with the Hands and Voices Board to complete a 3-year collaborative work plan by fall 2008.

D. PROGRAM CAPACITY

EHDI staff has prepared an ambitious Work Plan for the next three years. Indiana's program has three full-time employees (State EHDI Coordinator, UNHS Nurse Consultant, and one clerical staff) assigned to the program, and a large number (13) of professionals who participate in part-time work on behalf of the program, and two other organizations that provide project support to EHDI families (Hands and Voices) and professionals (Indiana Perinatal

Network). Outreach Services and First Steps Early Intervention also share resources and are always eager to partner in the delivery of services to families, children and professionals in Indiana. Members of the (volunteer) EHDI Advisory Committee are committed to making EHDI an outstanding program and have agreed to develop “working” subcommittees to assist on special project work. Finally, resources from the Centers for Disease Control (CDC), the National Center on Hearing Assessment and Management (NCHAM) and also the American Speech-Language-Hearing Association (ASHA) will be available and may assist the program by providing models of materials that can be used in our program. Indiana’s State EHDI Coordinator serves as a Region V representative for NCHAM and as the Chair for Division 9 (Childhood Hearing Loss) for ASHA. ISDH staff, consultants, committee volunteers and EHDI partners are aware of the program goals outlined in this grant and have voiced their support, recognizing that it will take a team to truly impact the lives of children and families in a positive and measurable manner over the course of time. Information shared in the Staffing and Management Plan section also provides support for the capacity of this program in achieving its plans.

E. STAFFING AND MANAGEMENT PLAN (see Additional Information, Organizational Charts)

The ISDH Genomics and Newborn Screening staff members, EHDI State Audiology Coordinator, UNHS Nurse Consultant, Regional Audiology Consultants, Parent Consultant, Information Technology Consultants and support staff who work directly with the EHDI program demonstrate significant expertise in the areas of: screening, tracking, identifying, providing intervention services to children diagnosed with hearing loss, and the genetics of hearing loss (see Additional Information: Vitas). The range of audiology experience among the State EHDI Coordinator and Regional Consultants includes; school based services, private practice, clinical and research positions as part of multidisciplinary cochlear implant teams at James Whitcomb Riley Hospital for Children, hospital based clinical and research services, outpatient rehabilitation centers, non-profit agency and aural rehabilitation services provided in the natural environment. In addition, the Director of the Genomics in Public Health/Newborn Screening Programs, is a trained Genetic Counselor who has worked in a variety of settings providing services and education to families, students and other professionals. The Information Technology Consultants, UNHS Nurse Consultant, and other ISDH NBS staff members have received considerable training related to EHDI issues from screening, tracking and follow-up, risk factors, data entry, and future areas of development. The Parent Consultant has a child with a hearing loss. Her expertise as a parent going through the EDHI process has made her a valuable resource to parents who are now facing the same journey

Each person within the UNHS/EHDI program has a specific role. The State EHDI Coordinator supervises the Regional Audiology Consultants, EARS Consultant, and Parent Consultant, conducts the follow-up for babies who do not pass UNHS or for babies who are at risk for delayed onset hearing loss, collaborates with state agencies and other interested parties regarding UNHS/EHDI issues, conducts outreach activities throughout the state, and collaborates with national organizations and professionals on methods to improve EHDI programs. The Lead Regional Audiology Consultant oversees the activities of the other regional consultant and supports the State EHDI Coordinator in other activities that are important for the program’s progress. The Regional Audiology Consultants provide technical assistance and consultation to hospitals and families in their region of the state. With the new EARS web-based reporting system, the Regional Consultants will have increased contact with the hospitals in their areas to offer support and training. The UNHS Nurse Consultant and the Clerical Assistant are responsible for entering Exceptions Monthly Summary Report (MSR) data and for follow-up for babies who do not receive UNHS. They will continue to enter data into the EARS system for hospitals that have not yet been trained or who don't have the necessary technology to enroll in the EARS program at the present time. The Parent Consultant assists with EHDI follow-up and directly contacts families of newly identified children to offer resources and support. The Information Technology (IT) Specialist spends his time developing the EARS database and collaborating with other IT personnel on utilizing the integrated UNHS/EHDI data.

Two additional positions, the EARS Consultant and the Follow-up Coordinator are requested in this grant opportunity. The EARS Consultant will provide additional assistance to hospitals that are having difficulty with data entry or have questions about the EARS application following ISDH training and provide on-site assistance to any hospital if needed. The Follow-up Consultant will assist the EHDI State Coordinator and the Nurse Consultant in the day-to-day management of alerts generated by the EARS system. With the increasing number of hospitals using EARS, the need for additional personnel to process alerts was identified as an important need for the success of the EARS application.

F. EVALUATION PLAN

Since the inception of UNHS program in Indiana in 1999, assessment and evaluation of progress has been ongoing. One of the main methods of evaluating the effectiveness of the program comes from data created from the UNHS database and, in the near future (EARS). The data items to be collected and analyzed will target the goals as set forth by the Centers for

Disease Control (CDC), the Joint Commission on Infant Hearing (JCIH), and Healthy People 2010 which include: 1.) to screen of all babies by one month of age; 2.) to complete follow-up evaluations to diagnose hearing loss before three months of age; 3.) to enroll all babies with diagnosed hearing loss into early intervention services by six months of age; 4.) to monitor all babies who are at risk for delayed onset of hearing loss; 5.) to establish a medical home for each child; 6.) to ensure that the rights of families are guaranteed through informed consent and decision making; 7.) to increase access to hearing rehabilitation and assistive technology; 8.) to increase the proportion of people who have timely hearing examinations; and 9.) to increase the number of people who are referred by their primary care physicians for hearing evaluations and treatment.

In order to provide appropriate services to children and families, Indiana will need to increase the capacity of available of providers who serve babies and toddlers with hearing loss and their families. Once person-centric early intervention data is received from First Steps, ISDH will gain a more specific perspective on the types of services being provided and the progress of children being serviced through early intervention data from First Steps. EHDI will then be able to assist in efforts to develop skilled providers at a much greater level.

Several strategies will be used to monitor the quality of data being entered into the UNHS database, EARS, and the ODS. 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 IU Lab for children who do not pass the hearing screening will be evaluated by comparing information to the Monthly Summary Reports received from each birthing facility. Because of the sophisticated nature of the EARS system, duplicate records (an issue with the UNHS data system) will become almost non-existent, as a child presented to the EARS system with incomplete information, must go through a staging and matching process. Each hospital using EARS will receive periodic data audits by EHDI personnel. This information will be shared with respective hospitals on their Annual Report Card. Hospital and audiology EARS trainings will be peer-reviewed (by email) and evaluated by attendees at the end of each training, and summarized in a written report at the conclusion of each year. The EDHI 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 also be asked to provide the EHDI staff with feedback regarding developed materials, presentations, and other outreach activities. All goals listed on the Work Plan will be evaluated for quantitative and qualitative progress at six-month intervals. Consultant activity logs will also be used to compare information that is put into the databases. 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.