INTRODUCTION

The purpose of this project is to reduce loss-to-follow-up at all stages of the Early Hearing Detection and Intervention (EHDI) process, most specifically in those babies who do not pass newborn hearing screening. Indiana's EHDI program, through support from federal entities (Health Resources and Services Administration [HRSA] and Centers for Disease Control [CDC]), the Indiana State Department of Health (ISDH), other State entities, private organizations and individual stakeholders has made significant strides in realizing early detection of hearing loss and intervention for children who have failed to pass newborn hearing screening and have subsequently been identified with permanent hearing loss. Numerous activities have led to success of screening, identifying and enrolling children into early intervention services: 1) EHDI legislation requiring a) all infants born in the state of Indiana to be screened for hearing loss at the earliest possible time, b) results to be reported to the Indiana State Department of Health (ISDH) in a timely manner, and c) implementation of a system of tracking and follow-up of babies referred from Universal Newborn Hearing Screening (UNHS) was implemented in 2000 2) The EHDI program, located in the Department of Genomics and Newborn Screening in the Division of Maternal and Child Health at the Indiana State Department of Health (ISDH) has received consistently broad support 3) The infrastructure of the EHDI program has been developed to maximize reduction in loss-to-follow-up at all stages in the EHDI process, and 4) EHDI system stakeholders have been highly responsive to achieving Universal Newborn Hearing Screening (UNHS), early identification and early intervention for the majority of Indiana's children.

The EHDI program recognizes the need to improve overall (national) performance on the newborn hearing screening objectives outlined on the *Healthy People (HP) 2020* plan: 1) screening for hearing loss no later than age one month (HP 2020 national target: 90.2%), 2) Receipt of audiologic evaluation no later than three months for infants who did not pass the hearing screening (HP 2020 national target: 72.6%), and 3) enrollment of infants with confirmed hearing loss for intervention services no later than six months (HP 2020 national target: 55.0%). While Indiana's newborn hearing screening and early intervention percentage rates are above the national target, there continues to be a need for improvement on all three objectives. The remaining portion of this narrative will outline Indiana's needs, methodology, work plan, proposed resolution of challenges, evaluation and technical support capacity, and organizational information pertinent to reducing loss to follow-up across the EHDI process.

NEEDS ASSESSMENT

Overview of Past and Current Major Activities:

Indiana's EHDI program has been working diligently since the establishment of the program in 2000 to ensure that all of Indiana's babies are screened, receive confirmatory diagnosis, and are enrolled in early intervention if found to have hearing loss. Numerous activities have been conducted to address concerns related to loss to follow-up.

From 2000-2004, the EHDI program was administered by one UNHS Nurse Consultant (in-office) and a network of part-time Regional Audiology Consultants. This model successfully established relationships and reporting protocols with all hospital birthing facilities and audiologists across the state participating in EHDI. A full-time EHDI Program Coordinator

(audiologist) was hired in August 2004 which resulted in consistent administration of the program and impact on the extremely high loss to follow-up rate of children in Indiana at that time. Fifty-four percent (54%) of babies born in 2004 were lost to follow-up from screening to diagnosis. That percentage decreased to a 35% loss-to-follow-up rate for babies born in 2005 and 15% loss-to-follow-up rate for babies born in 2006. Major activities in 2007 and 2008 included creation of a custom, web-based integrated data system, the hiring of a new EHDI Coordinator (the original coordinator had stepped down), and establishment of two new positions; EHDI Follow-up Coordinator, and Parent Consultant. Birthing facilities and audiologists received training on the EHDI Alert Response System (EARS) in 2008-09 that resulted in earlier reporting of screening and diagnostic results and improved data quality as compared to data received in the UNHS Access System that was used by the program prior to EARS.

In 2009 and 2010, additional follow-up staff was added to the existing staff. In late 2009, a bilingual (for Spanish) EHDI Parent Consultant and a Guide By Your Side (GBYS) Parent Program Coordinator were hired. With the EHDI Follow-up Coordinator and two Parent Consultants on staff, the ability to consistently contact families, primary care providers, early intervention programs, and audiologists (through letters, phone, and EARS system secured email) enabled additional reduction of loss to follow-up to be addressed in a more strategic manner. In response to Indiana's need to improve loss to follow-up and provide family support at all stages in the EHDI process, ISDH extended a contract to Indiana (IN) Hands & Voices for the two EHDI Parent Consultants, establishment of its Guide By Your Side program in Indiana, and for administration of the Indiana EHDI Family Conference. All three of the positions contracted by IN Hands & Voices to the EHDI program were designed to be filled by parents of children with hearing loss. The EHDI Parent Consultants conduct follow-up on children who do not pass newborn hearing screening to reduce loss to follow-up from screening to diagnosis and the GBYS program conducts follow-up with families of diagnosed children to assist EHDI with reducing loss to follow-up from diagnosis to early intervention and to provide support to families in the early post-diagnosis period. The EHDI Parent Consultants connected with 2,188 families which included over 6,700 letters being sent to parents and physicians and over 2,188 phone call attempts to families, primary care providers, early intervention programs, and audiologists during the 2010 calendar year. The Guide By Your Side program has enrolled 171 children since September 2009, which represents 45% of children identified through EHDI since September 2009. These families were assigned by the GBYS Program Coordinator, who has initial contact with families after diagnosis, to one of ten Parent Guides located across the state. Families who opt into the Guide By Your Side program when contacted by the GBYS Program Coordinator are provided with up to six hours of support from their Parent Guide. Additional details related to the Guide By Your Side Program will be discussed later in this narrative.

In 2009 and 2010, support from the Health Resources and Services Administration (HRSA) afforded Indiana the opportunity to participate in the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative for Newborn Screening and Epilepsy programs. Use of the PDSA (Plan-Do-Study-Act) model of improvement was employed to conduct small tests of change in EHDI follow-up. The EHDI program partnered with the St. Vincent Hospital System for participating in the collaborative and set up a 13-member NICHQ team (including EHDI staff) who determined and assisted in implementation of activities, evaluation and future directions. Indiana's participation in the NICHQ project led to use of a formal method for addressing quality improvement needs. Findings from the small tests of

change conducted as part of the NICHQ experience provided data that supported implementation of changes in the referral process Indiana had used since the inception of the EHDI program. One test of change conducted during the NICHQ Learning Collaborative included modification of the referral process for children not passing UNHS. The change enabled parents to schedule for diagnostic testing prior to being discharged from the hospital. This change was spread statewide and will be discussed in greater detail later in this section.

In 2010, the EHDI program became further engaged in quality improvement activities through a contract extended to Indiana by the Centers for Disease Control (CDC). Indiana and Iowa EHDI programs were invited to participate in the iEHDI (individual EHDI) project currently being conducted by the CDC to look at individual, child-centric de-identified information on 133 data items. The iEHDI project includes Indiana's sharing of data on all occurrent births in the 2010 calendar year and essentially provides a view to the CDC of individual children as they travel through the EHDI process from birth through early intervention (if identified with hearing loss). Historically, EHDI programs have provided aggregate data on children to the CDC through the annual CDC EHDI Survey. While this survey does provide a dashboard view of how successful State and Territory EHDI programs are in implementing "1-3-6," the evaluation of aggregate data is limited in its ability to impact specific program change and makes it difficult for states, as well as the CDC, to determine their specific needs for technical assistance. As evidenced by Indiana's participation in the iEHDI project, analysis of EHDI data at the individual level allows for a much deeper view of successes and needs for improvement than aggregate data can provide. However, for the purposes of this grant application, aggregate data will be provided.

Data on Babies born in 2009

Data discussed in the following paragraphs represents babies who were born in 2009. According to Vital Records, the occurrent birth rate of children born in Indiana in 2009 was 87,567. Demographic data based on maternal factors indicates that 76% of babies were born to non-Hispanic white mothers, 11% were born to non-Hispanic African American mothers, 8% born to Hispanic white mothers and the remaining 5% were born to mothers whose maternal race made up 2% or less of the demographic of mothers in Indiana. Of this birth cohort, 98.2% (85,925) were screened and 1,642 babies were not screened. Newborn screening is mandated by law in Indiana except for babies whose mothers refuse screening based on religious objection, which requires the signing of a religious waiver form. Tables 1a and 1b denote demographic data and reasons reported to EHDI through the EARS system for those babies not screened:

Maternal Race	Percentage
White (Not Hispanic)	76%
White (Hispanic)	8%
Black or African American (Not Hispanic)	11%
Other	5%

Table 1a: Maternal Race of Children born in Indiana

Reason Not Screened	# of Children
Equipment Problems	6
Home Births	1234
Hospital Error	9
Religious Objection	440
Unauthorized Refusal	18

Table 1b: Reasons for no UNHS

Of those babies screened, 1,986 (2.3%) did not pass newborn hearing screening and were referred for diagnostic audiology evaluation. Demographic data for children who did not pass newborn hearing screening and were therefore eligible for diagnostic audiology evaluation is provided in Table 2.

Maternal Age	**Percentage**
< 15 years	0%
15-19 years	13%
20-24 years	30%
25-34 years	43%
35-50 years	10%
Unknown	3%
Maternal Race	
White (Not Hispanic)	64%
White (Hispanic)	12%
Black or African American (Not Hispanic)	15%
Other or Unknown	8%
Maternal Education	
Less that HS	27%
HS Grad/GED	28%
Some College	24%
College Grad	17%
Insurance Coverage	
Private Insurance	38%
Medicaid	55%
Other or Unknown	7%

Table 2: Demographics for Children Not Passing UNHS

Indiana's protocol for newborn hearing screening includes one screening for all babies, a second screening just before discharge for those babies who did not pass the initial screening, and referral for diagnostic audiology evaluation for those who do not pass the second screening provided by birthing facility personnel. This protocol results in 1,800 to 2,000 referrals for diagnostic audiology annually. Hospital birthing personnel, audiologists, primary care providers and the EHDI program expends considerable time and other resources to ensure follow-up occurs for this group of children. Indiana's annual loss-to-follow-up data from screening to diagnosis has ranged from 15 to 22% for babies born 2006 through 2009. Indiana needs to reduce loss to follow-up from screening to confirmatory diagnosis to 10% or less by the conclusion of this grant period (March 2015). Activities designed to reduce loss to follow-up at this stage are outlined in the Work Plan section of this narrative. Follow-up data for children born in 2009 is displayed in Table 3.

Total Not Pass Screening	1986	Percentage
Normal Hearing	1314	66%
Diagnosed Hearing Loss	132	7%
Audiologic Diagnosis in Process	5	0%
Non-resident or Moved Out of Jurisdiction	26	1%
Infant Died	10	1%
Parents / Family Declined Services	48	2%
Parent / Family Contacted but Unresponsive	304	15%
Unable to Contact	147	7%

Table 3: Status of children born in 2009 who did not pass UNHS

Children who are diagnosed with hearing loss also receive a significant amount of attention from the EHDI program. A primary reason for identifying children with hearing loss as early as possible is so that they may develop communication skills and academic success on par with typically-developing peers or, for those children who have co-existing conditions, maximization of their potential to develop these same skills. Children who are lost to follow-up from diagnosis to intervention are of concern because of the possible lost opportunity of these children to advance their development of communication, social and other domains to a level that sets them up for success in school and life. The EHDI program has met with several challenges in adequately monitoring and serving this population of children and their families. The Family Educational Rights and Privacy Act (FERPA) and Part C regulations, according to the State Part C (First Steps) Coordinator do not allow for sharing of child-centric information without individual signed parental releases of information making it difficult for EHDI to learn the early intervention status of children diagnosed with hearing loss who are enrolled in the public Part C system. Also, children who pass newborn hearing screening but are later found to have a hearing loss and are referred to the Part C system are not generally reported to the EHDI program by Part C. It is encouraging that when EHDI is able to secure a signed parental release of information, the Part C program, will send a copy of the child's Individualized Family Service Plan (IFSP) to the EHDI program. The IFSP includes information about date of enrollment into Part C, types of services the child will receive, and expected outcomes. This information is helpful to the EHDI program and is entered into EARS when received. Activities related to resolution of the challenges that EHDI experiences related to obtaining early intervention information will be discussed later in this narrative.

Fifty-six percent (93/167) of children who were born in 2009 and have been diagnosed with hearing loss are known to have enrolled in Part C (First Steps) services. Demographic data for all children diagnosed with hearing loss is compared to those children enrolled in First Steps in Table 4.

	All Diagnosed Percentage (N=167)	Diagnosed & Part C Percentage (N=93)
Maternal Age		
15-19 years	7%	9%
20-24 years	31%	28%
25-34 years	47%	52%
35-50 years	8%	8%
Unknown	7%	4%
Maternal Ethnicity		
Hispanic or Latino	14%	15%
Not Hispanic or Latino	83%	85%
Unknown	3%	0%
Maternal Race		
White (Not Hispanic)	66%	68%
White (Hispanic)	11%	11%
Black or African American (Not Hispanic)	12%	6%
Other or Unknown	11%	15%
Maternal Education		
Less that HS	18%	20%
HS Grad/GED	30%	29%
Some College	25%	23%
College Grad	21%	24%
Unknown	7%	4%
Insurance Coverage		
Self-Pay	5%	2%
Private Insurance	43%	48%
Medicaid	43%	43%
Other or Unknown	9%	7%

Table 4: Comparison of demographics of children diagnosed with permanent hearing loss and those diagnosed who have also enrolled in Part C (First Steps)

Discussion of Needs Related to Loss to Follow-up

Reduction in loss to follow-up is impacted by numerous factors in Indiana such as maternal demographics, parental awareness during the pre-, peri- and post-natal periods of the importance of hearing screening, results of screening, and the need for follow-up after failure to pass newborn hearing screening. Other issues include: child health, collaboration among EHDI providers, system barriers to successfully completing the EHDI process, adequate family support and successful communication between the EHDI program and families, knowledge and training of the screening, diagnostic, intervention, and medical home workforce, stakeholder compliance

in reporting child-centric information to EHDI, and the EHDI program's ability to conduct adequate monitoring, surveillance and evaluation activities through its EARS database.

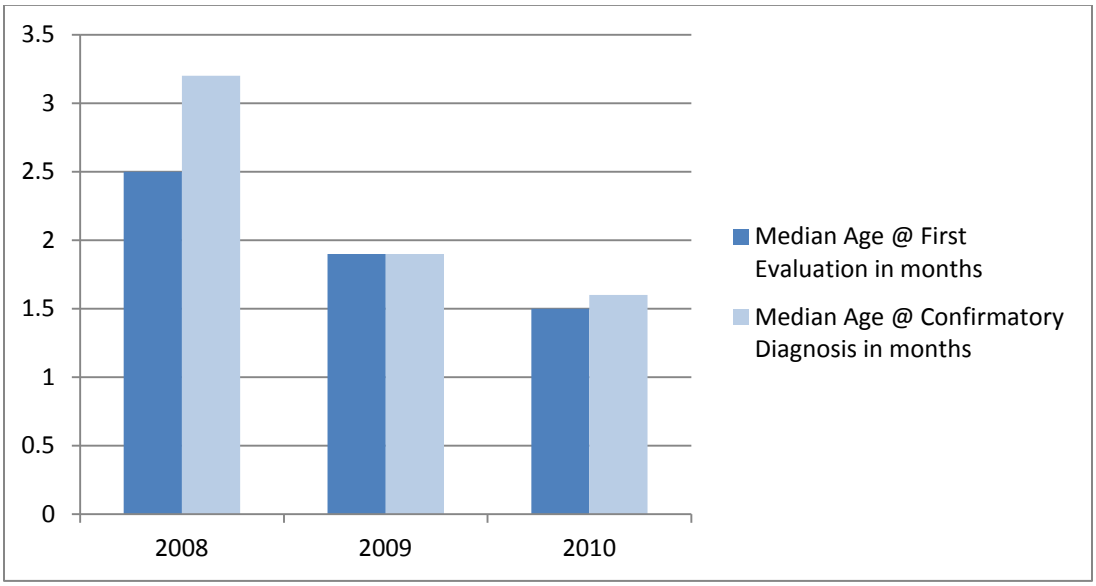
Data for babies born in 2009 indicates that 1,642 babies did not receive a newborn screening. While religious waivers were signed for 440 of those babies, there is continued concern when any baby's hearing is not screened because of the impact of undiagnosed hearing loss. In fact, three children who did not receive UNHS because of religious objections were later identified with hearing loss. There are approximately 53 nurse midwives and certified professional midwives who may be providing birthing services in Indiana. Presently, only three homebirth practices are providing newborn hearing screening as a service to their clients. Reportedly, many of these professionals refer babies to hospital birthing facilities and audiologists for newborn hearing screening, however that number is not well quantified. The EHDI program needs to impact this group of professionals who do not have hearing screening equipment in a manner that will encourage either employment of newborn hearing screening technology or a set referral practice to a facility that has equipment and trained screening personnel.

Analysis of demographic information for mothers whose children were born in 2009 indicated that mother's ethnicity, educational level, and insurance coverage were all significantly correlated to not receiving UNHS. Mother's who were non-hispanic, received less than a high school education and did not have public or private health insurance were significantly more likely to have children who did not receive newborn hearing screening. Analysis of demographic information for mothers whose children were born in 2009 and did not pass newborn hearing screening and for whom follow-up was recommended revealed that mothers who did not have public or private health insurance (were self-pay) were less likely to pursue follow-up testing for their children. Additional data review indicates that certain counties within Indiana including LaGrange and Adams have the highest rates of children without newborn hearing screening and highest rates of children who did not pass newborn hearing screening and did not receive follow-up. Activities, resources, and supports will be developed to address these findings to improve screening and follow-up rates.

In 2007, the EHDI program, through its Parent Consultant, began to contact families whose children did not pass newborn hearing screening. Through this activity, it was quickly determined that the following issues were contradictory to babies receiving early follow-up after newborn hearing screening: 1) Delayed reporting of children to the EHDI program 2) Difficulty reaching a significant number of parents because of changes or lack of information related to the baby's name, their contact information (i.e. phone number, residence address) and/or their primary care provider [who often acts as a secondary resource of family contact information] 3) Lack of follow-up activity because parents were waiting for a phone call from someone (i.e. Part C system or primary care provider) for further instruction related to follow-up and 4) confusion, doubt or lack of real concern related to the validity and reliability of their baby's hearing screening results. Information gained from having contact with parents through the EHDI program led to hiring an additional parent consultant (who is bilingual for Spanish). The EHDI program currently has two EHDI Parent Consultant positions. The role of these individuals is to contact all mothers of all babies who do not pass newborn hearing screening shortly following discharge from the birthing facility to discuss and answer questions about screening results and follow-up, to clarify that demographic and other information contained in the EARS database is

still valid (or has changed) and to confirm that the child is scheduled for a diagnostic audiology evaluation appointment. The Parent Consultants assist families who are not yet scheduled for follow-up. Data for parent consultant contact with families of babies who did not pass newborn hearing screening includes more than 2,188 families contacted in 2010.

Data in Graph 1 below describes the overall improvement in median age for first evaluation and age of confirmatory diagnosis (normal or permanent hearing loss) for children born in 2008, 2009 and 2010 calendar years.



Graph 1: Median Age of first evaluation and age at confirmatory diagnosis for children not passing UNHS from 2008-2010.

While age at which children receive their first evaluation and confirmation of hearing status continues to improve, birth complications that necessitate neonatal intensive care unit (NICU) stays is one factor that often contributes to delayed initial screening and delayed age of diagnostic audiology follow-up. Of babies born in 2009 who did not pass newborn screening, 13% received newborn hearing screening after five days of age. Follow-up for the "sickest" babies in this population is often compounded by other medical, health, and developmental concerns unrelated to hearing loss and qualifying the baby's hearing status may not be a priority. Attention is needed to better quantifying and qualifying this population of Indiana's children. In addition, the ability to offer diagnostic assessment for children who are long-term NICU patients needs to be explored to improve the proportion of children receiving diagnostic follow-up at to reduce the age at diagnosis.

An additional issue related to child health that impacts the process of reaching confirmatory status for babies who do not pass newborn hearing screening is otitis media with effusion (fluid in the middle ear). Education among primary care providers, otolaryngologists, audiologists and parents continues to be needed to ensure that all babies who have a permanent hearing loss are diagnosed at the earliest possible time and children with chronic otitis media receive diagnostic audiologic evaluations once the ears are healthy and clear to confirm hearing status.

Ongoing collaboration between agencies and entities ("the system") that serve children who have or may have hearing loss continues to be an important aspect of working through barriers that impact a family's experience as they go through the EHDI process. Significant issues that continue to impact timely occurrence of EHDI and influence a family's encounter with the EHDI process [beginning with birth through enrollment in intervention, if a child is identified with hearing loss] include 1) coordination of follow-up 2) funding of follow-up services 3) sharing of child-centric information between agencies and entities and 4) disagreement and conflict among some entities related to parent education and intervention for numerous aspects of hearing loss (i.e. technology, intervention services, communication and education methodologies, cultural and other values-related aspects).

Successful coordination of follow-up services is an important aspect of ensuring that families engage in the EHDI process and are not lost to follow-up. Previous to October 2010, babies who did not pass newborn hearing screening or who passed but were at risk for acquired hearing loss were referred to the State's Part C (First Steps) system for service coordination of audiology follow-up. Effective October 1, 2010, First Steps, for financial reasons, along with several other cuts, ceased to fund (as the payer of last resort) or coordinate diagnostic audiology evaluation follow-up for babies who did not pass newborn hearing screening or who were at risk. The EHDI program responded to these changes by 1) increasing the responsibility of EHDI Follow-up staff (Parent Consultants, EHDI Follow-up Coordinator, GBYS Coordinator [and Parent Guides]) to ensure that families connect with diagnostic audiology follow-up and early intervention (once diagnosed) 2) training EHDI staff, birthing facility, audiology and early intervention personnel on pay sources and changes to EHDI protocols and 3) instituting statewide the direct referral to audiology model that had been tested by Indiana during involvement in the NICHQ Learning Collaborative. EHDI recommended that all birthing facilities directly refer (and preferably, schedule) all babies to a Leve1 1 audiology center. The majority of birthing facilities (77%) chose to follow EHDI's recommendation of direct referral to audiology, while 16% of facilities refer babies to their primary care provider, 6% are conducting an outpatient rescreen and then referring on to the primary care provider or audiology, and one facility is referring babies to their neurology department for follow-up. The term "Level 1," as used by Indiana EHDI, denotes those audiology facilities that have the capability and regularly use oto-acoustic emissions, auditory brainstem response (tones, clicks, bone conduction) and high-frequency tympanometry in infant assessment of hearing. It is important to note that in the absence of First Steps' statewide coordination of follow-up for babies who did not pass newborn hearing screening, birthing facilities, primary care providers, audiologists and EHDI follow-up staff now share full responsibility for assisting families in completing follow-up. This work has resulted in further developing and supporting existing relationships with EHDI system partners and stakeholders and has significantly increased the timeliness and amount of contact the EHDI program has with other stakeholders (including parents) to ensure that babies and their families have the safety net that EHDI provides in place. Ongoing education and training of EHDI system partners and stakeholders is a need that will continue to be addressed as EHDI seeks to ensure that Indiana's loss- to- follow-up rate is reduced to 10% or less by the end of this grant period (March 2015). Data related to the impact of the statewide change in referral process is provided in the Methodology section of this narrative.

Funding of follow-up services is an ongoing issue for many families and may impact a family's decision to pursue follow-up diagnostic audiology evaluation. Pay source data was

available on 1,921 of the 1, 986 babies born in 2009 who did not pass newborn hearing screening. This data is available in Table 2. Note that those families who do not have insurance (self-pay) may be at particular risk for being lost to follow-up as they may not have the ability to fund follow-up audiology services. It also was noted that a large majority (86%) of families who signed the religious waiver refusing UNHS did not have insurance and would have had to pay for the screening themselves. EHDI is investigating opportunities to provide screening for this group of families at a free or reduced cost. The EHDI program needs to continue to work with State agencies and other entities to ensure that screening and follow-up services are authorized, funded and occur in a timely, consistent manner. The EHDI program, through its EHDI Follow-up Coordinator and Parent Consultants, needs to continue to identify and resolve issues related to screening and follow-up that may be financial in nature and needs to continue to assist parents in securing services.

The State's Part C program (First Steps) (located at the Family and Social Services Administration [FSSA]) coordinates early intervention services and acts as the payer of last resort for children birth to three who have been diagnosed with hearing loss. Once diagnosed, a child is generally eligible for the following services: intake assessment, service coordination, earmolds, hearing aid evaluation, hearing aids (except for the soft-band BAHA), hearing aid supplies and accessories, hearing re-evaluations, and several types of direct early intervention services. The State's Children with Special Health Care Services (located at ISDH) and Medicaid program (located at the Family and Social Services Administration [FSSA]) fund hearing evaluation, hearing aid evaluation, hearing aids (including the BAHA), hearing aid supplies and accessories and direct early intervention services for children who are financially eligible for those programs.

Sharing of child-centric information between agencies and entities in Indiana continues to need resolution. Through the Health Insurance and Portability Accountability Act (HIPAA), the EHDI program is able to share information with EHDI stakeholders involved in a child's care as it relates to treatment, payment or operations. Reciprocal sharing of child-centric data between the EHDI program and birthing facilities and EHDI to the Part C system is not an issue. However, the State's Part C system has cited that the Family Educational Rights and Privacy Act (FERPA) and Part C regulations prohibit Part C from sharing data (even for children referred from EHDI) with the EHDI program unless a signed parental release is provided. Past attempts to have Part C intake and service coordinators incorporate a reciprocal release with families referred from UNHS have been unsuccessful. The lack of reciprocal sharing of child-centric data without a release between the EHDI and Part C programs continues to be of concern, particularly since the loss-to- follow-up rate from diagnosis to early intervention in Indiana continues to indicate that 25% of diagnosed children are lost to follow-up (LTF/D for babies born in 2009). Indiana instituted several strategies during the last reporting period including hiring of a nearly full-time EHDI Follow-up Coordinator and contracting with Indiana Hands & Voices to assist EHDI with parent follow-up by providing a second (bilingual) Parent Consultant and the Guide By Your Side program. All of these strategies have resulted in success towards impacting loss to follow-up. Still, Indiana needs further resolution of loss to follow-up between screening and diagnosis and diagnosis and early intervention. The EHDI program has agreed to take the lead on creating a Universal Release of Information that will be designed for use by agencies, audiologists, and other providers to obtain a parent's signature for reciprocal sharing of

their child's information between EHDI and other State entities that have responsibility for serving children with hearing loss.

Successfully reaching families of children who did not pass newborn hearing screening, who passed, but have a risk factor for acquired hearing loss or whose child has been diagnosed with hearing loss continues to be a significant challenge. In addition to continuing the contractual relationship with Indiana Hands & Voices to provide two EHDI Parent Consultants and the Guide by Your Side program, the EHDI program will partner with IN Hands & Voices by using their social media venues to connect with parents. The EHDI program will post EHDI-related facts, information and events on the IN Hands & Voices Face Book page and on IN Hands & Voices Twitter page as a method for increasing communication with parents.

The EHDI program needs to further develop relationships with community partners so that families who are at risk for being lost to follow-up receive adequate support from larger State systems and collaborating partners. To this end, the EHDI program will work with the Maternal Infant Early Childhood Home Visiting program (and specifically with their partner programs, Healthy Families Indiana [HFI] and Nurse Family Partnerships [NFP]), the Early Childhood Comprehensive System (a.k.a. Sunny Start) and Indiana Hands & Voices to increase family support programming for families involved in the EHDI process.

The EHDI process, especially for those families whose children are diagnosed with hearing loss, can be challenging. EHDI's observation of disagreement and conflict among some entities related to issues of hearing loss (or deafness) and the impact it appeared to be having on a family's securing of services led to a decision to provide a formal family support mechanism through the EHDI program. Subsequently, in 2009, the EHDI program, with support and funding from HRSA, contracted with Indiana Hands & Voices for provision of parent-to-parent family support activities that would support and engage families in the EHDI process, reduce loss to follow-up between screening and diagnosis and diagnosis and early intervention, and connect families and other valuable resources (as judged by each family). The EHDI program supports a parent's right to have access to comprehensive information about hearing loss and deafness, the right to receive unbiased information about the numerous aspects related to raising a child who is deaf or hard of hearing, and the right to make decisions for their child and family. The Indiana Hands & Voice Guide By Your Side program reflects the same core values as the EHDI program related to parents' rights and has been highly successful in working with Indiana's families by provided unconditional support, unbiased information about resources and services, guidance on "next steps" after diagnosis of hearing loss, connection to resources including other parents and individuals who are deaf or hard of hearing (if the parent chooses), assistance in navigating and arriving at early intervention enrollment and modeling parent empowerment and advocacy behaviors. As previously mentioned, 45% of families of children diagnosed with hearing loss through the EHDI program in the past two years have chosen to be matched with a Guide by Your Side Parent Guide. Evaluation of GBYS enrollment, parent feedback regarding the EHDI Family Conference and their experience in the GBYS program, and the current workload of the program has resulted in a recommendation to add a Family Outreach Coordinator to the existing GBYS network. This position will involve ensuring that families transitioning from GBYS are connected to other family support activities if desired, attempting to contact families that the EHDI program has not successfully reached to ensure that programming has ensued, planning

and implementing annual state wide family programming (including the EHDI Family Conference), and assisting GBYS Parent Guides with their regional events as needed.

Indiana Hands & Voices and its Guide By Your Side program is having a tremendous, positive impact on Indiana's EHDI system, but more importantly, on individual families. The contract with Indiana Hands & Voices for two EHDI Parent Consultants, the GBYS program and the annual EHDI Family Conference needs to continue if Indiana is to continue to engage parents in their child's process so that loss to follow-up is reduced and the likelihood of successful child and family outcomes is enhanced. A list of training activities, events and accomplishments of Guide by Your Side since September 2009 is included in Attachment 1. Activities included presentations at national and state meetings, co-authoring articles for state newsletters and resource materials, participating on advisory boards and committees (including participation in the NICHQ Learning Collaborative), hosting the annual EHDI Family Conference, and hosting 6 additional regional family-focused social events. In addition, feedback from the GBYS Family Survey that is completed by families at the conclusion of their enrollment in GBYS is reviewed and tabulated. Although only a handful of surveys have been returned, results indicate that families are quite pleased with the support being provided by GBYS. A few comments from parent questionnaires are, "[She] met when we could both find time in our schedules. We appreciated her flexibility." "We were already involved with our school when we met [our Parent Guide]. She was a huge help when helping us prepare for our first school meeting in regards to an IEP!" and "Overall, I really appreciate all the help from the Parent Guide. It is very beneficial for parents like me to get help through tough situations, get help and regain faith."

In order to assure a sufficiently trained, knowledgeable and highly qualified workforce, ongoing education and support are needed. The EHDI program is challenged by the continuing education and information needs of an EHDI system that serves nearly 85,000 babies and families per year (through screening), approximately 100 birthing facilities, more than 100 audiologists, numerous primary care providers and other physicians, 92 local health departments, and the many providers of early intervention and special education (which includes only a minority who specialize in providing intervention to children with hearing loss). The EHDI program has provided ongoing training to birthing facilities and local public health personnel through EARS trainings, web technology and face-to-face trainings and to Part C personnel (audiologists and early interventionists) through bi-annual EHDI forums. EHDI program staff also provides education to undergraduate and graduate audiology student training, nursing and residency programs. While the training of birthing center (who also receive ongoing technical assistance from the EHDI Follow-up Coordinator and support from the EHDI Regional Audiology Consultant Network) and public health personnel appears sufficient with the current methods EHDI has in place, considerable attention is needed to the ongoing continuing education needs of the remaining workforce that impacts Early Hearing Detection and Intervention. The Principal Investigator of the Promoting Achievement for Students with Sensory Loss (PASS) project, a Department of Education grant that is being administered at Indiana State University, has agreed to partner with the EHDI program and Indiana Hands & Voices to develop and implement a two-year professional training plan on hearing loss for in-service education of audiologists, early interventionists, educators, related personnel and administrators. Additionally, the EHDI program is working with the Indiana American Academy of Pediatrics Chapter Champion to develop a three-year plan for increasing awareness and education among primary care providers and other medical professionals.

Stakeholder compliance in reporting correct and complete child-centric data to the EHDI program continues to need attention. The EHDI program, with assistance from Information Technology (IT) staff, continues to monitor reporting of information in the EARS database by all EHDI providers. The EARS (EHDI Alert Response System) database is integrated with the larger Integrated Data System (IDS) which includes information from Vital Records and from other newborn screening programs (i.e. heel stick, cystic fibrosis). Child information that is entered into EARS is matched with existing records, such as the heel stick card and birth certificate record. While the IDS successfully matches 90% of all children entered into the data system, duplication of EARS files does occur and is an ongoing problem. Another challenge in maintaining strong data quality is identifying user entry errors. Monitoring and matching activities are shared by the EHDI Follow-up Coordinator and IT staff. The EHDI Follow-up Coordinator spends considerable time and attention on data quality and data analysis which creates a challenge to completing her other duties related specifically to EHDI follow-up.

Current users of the system include EHDI staff, birthing facility reporting personnel, audiologists, Early Intervention System Point of Entry (SPOE) offices, and Guide By Your Side Parent Guides. The EHDI program receives newborn hearing screening results for children by two methods: 1) Hearing screening results are recorded on a baby's individual heel stick card that is sent from the birthing facility to the Indiana University Laboratory, and 2) Hearing screening results are reported through the EARS database by the birthing facility on babies whose status is considered exceptional—the baby has either not been screened (for any reason) or has been screened but did not pass or passed but presented with a risk factor that could lead to acquired permanent hearing loss. Ninety-seven of ninety-nine hospitals and birthing facilities directly enter child-centric and summary data into the EARS database to report babies with a screening status exception. The two facilities that are not directly entering their data complete a paper report monthly and fax that into the EHDI program. EHDI support staff then enters the data into EARS and appropriate follow-up begins.

In addition to birthing facilities, audiologists also constitute a large group of EARS users. Since the inception of EARS, 122 audiologists (who work in Indiana and neighboring states) have reported DAE results to the EHDI program. Data related to the reporting of Diagnostic Audiology Evaluation (DAE) results, whether reported into EARS or by fax is included in Table 5.

Calendar Year	Children Not Passing UNHS	Children with Diagnostic Results
2009	1,986	1,076 (54%)
2010	2,204	1,453 (66%)

Table 5: Proportion of children in 2009 and 2010 with diagnostic results

In 2010, 80% of DAE forms were entered directly into EARS by audiologists who conducted follow-up. DAE forms that were directly entered into EARS (80%) were reported by 52% of the total number of audiologists (122) listed in the EARS database. In other words, 80% of DAE forms were entered by half of the audiologists who are listed in EARS.

Other current EARS users include the 9 Part C (First Steps) System Point of Entry (SPOE) offices located regionally and the 10 GBYS Parent Guides, also located regionally.

Identified individuals at each of the Part C SPOE offices use EARS to receive and respond to EARS-generated secure email from EHDI staff (SPOE staff receive a notification in their regular email that they have a message in EARS). Recently trained to use EARS for reporting, the GBYS Parent Guides use EARS to report short (excluding audiology results) and long-term follow-up data onto an EARS Outcomes form that is attached to the Child Health Information Profile (CHIP) of each child whose family has opted into GBYS. The GBYS Parent Guides also use EARS to receive and respond to EARS emails that enable secure communication to occur between the GBYS Program Coordinator and Parent Guides as needed. All EARS users receive their primary EARS technical support from the EHDI Follow-up Coordinator.

EHDI program staff is highly dependent on the EARS database as a tool to monitor and track children and to conduct surveillance and evaluation activities. The EHDI program has received funding from the Centers for Disease Control (CDC) for further development of Indiana's monitoring and surveillance system (EARS). In order to garner the full potential of this system as a tool for reporting, monitoring, tracking and providing data, EHDI program staff is working with IT staff to complete an extensive set of data reports. Once these reports are completed, it is anticipated that the current EHDI Follow-up Coordinator and the EHDI Program Director will generate detailed data and work with epidemiological staff to analyze data. The ability to narrowly analyze Indiana's EHDI data will assist the program in conducting evaluation activities related to the impact of EHDI, enhance follow-up at all stages of the EHDI process, provide a platform for widespread sharing of data analyses with the broader EHDI community (i.e. state, national) through presentations and publications, and allow the EHDI program to more confidently make decisions regarding course corrections and future endeavors. However, in order for current EHDI staff (specifically the EHDI Program Director and EHDI Follow-up Coordinator) to have sufficient time to "work" with Indiana's data, the EHDI program needs to add a new part-time audiologist (with a title of Program Specialist) to assist in EHDI follow-up by assuming some of the duties of the current EHDI Follow-up Coordinator.

METHODOLOGY

A primary reason for the existence of EHDI programs is to ensure that children who have hearing loss are found early and receive programming that will result in a fulfilled life in spite or because of having a hearing loss. It is important to know if efforts of the EHDI program and system are impacting the baby, family and system in the ways intended and, if so, whether these results will produce positive outcomes as judged by those most significantly impacted by EHDI, children and their families. The Indiana EHDI program will conduct ongoing measurement of its attempts to improve the quality of the EHDI process so that it may be determined whether improvement efforts are: 1) resulting in the desired outcome, 2) contributing to any unintended results in other parts of the EHDI process or system, and 3) indicating that any additional effort needs to made to bring outcomes into a range that is acceptable by either scientific or professional standards in the EHDI field.

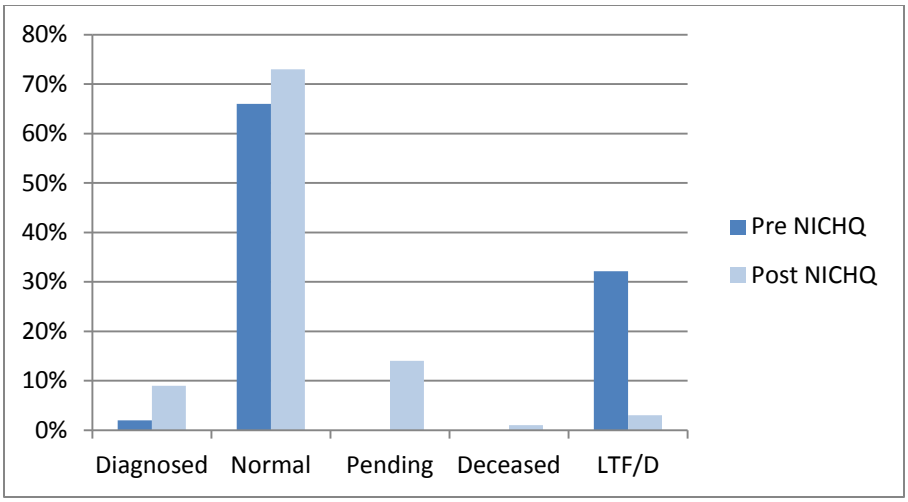
The EHDI program will use two primary strategies to measure and improve upon the quality of the EHDI program, process, and system in terms of structure (i.e. accessibility of resources), processes (i.e. the delivery of audiology follow-up services), and outcomes (i.e. the loss-to-follow-up rate in each of the Part C System Point of Entry regions across the state). These

strategies include the 1) Plan-Do-Study-Act (PDSA) model, and 2) Comparison of current to past performance of individual facilities on key performance indicators (i.e. percentage of babies with a did not pass result who were reported in EARS within 5 days of screening at a given facility) as a method to encourage better performance.

The EHDI program learned how to implement the Plan-Do-Study-Act model while participating in the NICHQ learning collaborative. PDSA uses cycles of small, rapid tests of change to access the impact of a change on a current structure, process or outcome. With this model, generally, one or more PDSA cycles are conducted and the results are analyzed by a team of dedicated participants who are knowledgeable about the systems of care in which the PDSA is being conducted, and then decisions are made about whether this change should be introduced to the system or, in the case of a State EHDI program, statewide.

Three questions are asked prior to initiating each PDSA cycle are: 1) What is the goal? 2) How will we know when the goal has been reached? and 3) What will be done to reach the goal? The planning phase of the PDSA cycle involves analysis of baseline data, clarifying the nature and scope of the problem, determining what changes could be made, making a plan for a specific change, and deciding who should be involved, what should be measured and where the strategy will take place (i.e. birthing facility). The change is implemented and data is gathered and analyzed to determine if the change has been a failure or success as implemented. At this point, a decision is made to either implement the change or change some aspect of the change and test that change through another PDSA cycle.

One small test of change implemented by Indiana during the NICHQ learning collaborative provided the EHDI program with data that assisted in "making the case" for instituting a major change, *direct referral to audiology,* to the statewide EHDI system in a period of just over one month's time. As discussed earlier in this narrative, on October 1, 2010, the State's Part C system ceased to coordinate or fund follow-up for babies who did not pass newborn hearing screening. The EHDI program recommended that birthing facilities and primary care providers directly refer babies who did not pass the hearing screening to an audiologist for diagnostic audiology evaluation, preferably prior to the baby's discharge from the birthing facility. Graph 2 shares data that compares baseline data collected for the NICHQ learning collaborative. The baseline data represents children born at the participating hospital in 2007 who were referred to Part C for follow-up from UNHS. Post NICHQ data represents children born between April 2010 and March 2011 born at the same hospital and were referred directly to an audiologist for follow-up from UNHS. This data demonstrates improvement in the overall EHDI process as evidenced by the significant decrease in the percentage of children lost to follow-up and the increase in percentage of children diagnosed with hearing loss.



Graph 2: Comparison of pre and post NICHQ data

While working on the NICHQ project, it was evident that the hospital staff appreciated the data provided by EHDI and used the data to educate staff members about the importance of their role in not just screening but also in scheduling appointments and ensuring that families knew the next step in the EHDI process. In order to share this type of feedback with all birthing facilities, ISDH IT staff is in the process of developing a feedback module on key performance indicators (such as screening and follow-up rate) that individual hospitals will be able to view on the home page of their individual EARS account. In addition once annually, a summary of performance (from activities conducting for the preceding twelve months) will be mailed to each facility's birthing unit manager and to the facility's head administrator.

Indiana's experience in the NICHQ learning collaborative provided insight into the benefits and challenges of quality improvement activities. Benefits include learning about and using a quality improvement strategy to assess EHDI structures, processes and outcomes, working with a highly-committed team to evaluate and improve EHDI in Indiana and gathering data in a relatively short timeframe for use in timely decision-making. EHDI's experience in the NICHQ project also suggests that certain challenges exist when incorporating quality improvement activities as a regular programming activity such as 1) securing sufficient staff and time to conduct quality improvement activities in an intensive fashion, 2) assuring stakeholders involved in the activities that the effort is worth the result, and 3) determining how to implement changes in a manner that is not too painful for stakeholders in terms of time, effort and other resources *and* can position the change to be successful and effect the intended result to the greatest possible extent.

WORK PLAN

The following work plan was designed for use from April 2012 through March 2015 and addresses the needs listed in the Work Plan (Table 6) as well as some additional opportunities for improvement:

Goal 1	**Measures of Success**
The Indiana EHDI system will work collaboratively to ensure that 97% of babies receive newborn hearing screening before age one month.	● 97% of babies born in 2013 will receive newborn hearing screening before age one month. ● 90% of the children born in 2014 will have documented UNHS results available to EHDI staff ● By June 2013, one hospital will be transmitting UNHS results electronically to ISDH on all children ● By September 2013, EARS will create automatic alerts based on electronic UNHS results received from pilot hospitals ● By Jan 2014, 90% of hospitals will be transmitting UNHS results electronically to ISDH on all children
Objectives	**Activities/Steps**
A) By Jan 2014, screening results will be received by the EHDI program on all children screened at all birthing facilities	1) Work with vendor to develop plan for implementation 2) Work with screening facilities to ensure capacity for sharing screening results directly from hearing screening equipment 3) Pilot direct sharing of screening info in one hospital system 4) Add one additional hospital system in each of Indiana's regions 5) Ongoing study of results and process modifications as needed 6) Spread statewide **Program Staff Responsible**: IT Staff, EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist

Objectives	Activities/Steps
C) By Oct 2012, capacity for screening by midwife personnel will increase by adding loaner screening equipment to at least three midwifery practices that are currently not screening newborns	1) Put out competitive application for loaner screening equipment use 2) Review applications and select recipients 3) Complete contract process with each facility 4) Ship or bring equipment to facility **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants
D) By Sept 2012, design updated hospital training and provide at least 4 webinars annually.	1) Update existing or create new presentation 2) Place on website (www.hearing.IN.gov) 3) Invite personnel to participate in one of four live webinars annually **Program Staff Responsible**: EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants
E) By March 2016, 98% of birthing facilities will use EHDI-designed materials with parents that emphasize the importance of UNHS and follow-up.	1) Continue to provide EHDI brochures (General FAQs and Referral brochure {if baby needs diagnostic follow-up] in English and Spanish to ensure that screening and any recommended follow-up occurs) to all birthing hospitals, birthing facilities and known midwives 2) Increase the number of birthing facility prenatal classes that are using the Loss and Found DVD by sharing with prenatal class coordinators during face-to-face visits 3) Increase the number of hospitals that are using the Loss and Found DVD (currently 30/98 use) during above mentioned face-to-face visits **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants

Goal 2	Measures of Success
The Indiana EHDI system will work collaboratively to ensure that no less than 75% of babies who do not pass newborn hearing screening receive confirmatory diagnosis of hearing status before age 3 months	● Attempts will made to contract 100% of families of babies who do not pass within one month of notification in EARS ● 100% of families who have not yet received follow-up will be contacted within 75 days of first contact ● 75% of NICU and 75% of non-NICU babies will receive confirmatory diagnosis before age 3 months ● The percentage of babies lost to follow-up will decrease to 10% or less from screening to diagnostic audiology
Objectives	**Activities/Steps**
A) Annually, the EHDI program will attempt to contact 100% of families of babies who do not pass newborn hearing screening and are reported to the EHDI program and who have not yet received diagnostic follow-up will be contacted by the EHDI program within one month of notification in the EHDI EARS system	1) Contact is attempted with families and primary care physicians (PCP) by phone and letter per EHDI protocols **Program Staff Responsible:** EHDI Parent Consultants
B) By March 2015, when diagnostic results are not received for children who do not pass newborn hearing screening by the EHDI program within 75 days of initial EHDI program contact, the EHDI program will attempt to re-contact no less than 100% of the remaining families by phone and letter	1) Contact is attempted with family and PCPs by phone and letter per EHDI protocols 2) Contact is attempted with audiologist with whom diagnostic testing was scheduled if provided by hospital **Program Staff Responsible:** EHDI Parent Consultants, EHDI Follow-up Coordinator, EHDI Program Specialist

Objectives	Activities/Steps
C) By March 2015, 75% of Indiana non-NICU babies not passing UNHS will receive a confirmatory diagnosis by 3 months of age.	1) Recommendations will be provided to physician community in one annual presentation 2) EARS data management system will be used to track children 3) Communication with parents, physicians, audiologists per EHDI protocols will be followed to ensure follow-up **Program Staff Responsible:** AAP EHDI Chapter Champion, EHDI Director, EHDI Parent Consultants, EHDI Follow-up Coordinator, EHDI Program Specialist
D) By March 2015, 75% of NICU babies will receive a confirmatory diagnosis by two months post-discharge.	1) Recommendations will be provided to physician community in one annual presentation 2) EARS data management system will be used to track children 3) Communication with parents, physicians, audiologists per EHDI protocols will be followed to ensure follow-up **Program Staff Responsible:** AAP EHDI Chapter Champion, EHDI Director, EHDI Parent Consultants, EHDI Follow-up Coordinator, EHDI Program Specialist
E) By March 2015, the percentage of children who are born in 2013 and who are lost to follow-up or documentation between screening and confirmatory diagnosis will decrease to 10% or less	1) By March 2013 at least 2 lost to follow-up characteristics will be identified and 2 new activities (such as educating families through county health departments or physician's offices with large lost-to-follow-up rates) to improve access to services will be implemented. **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, GBYS Program Coordinator, GBYS Family Outreach Coordinator

Goal 3	Measures of Success
The Indiana EHDI system will work collaboratively to ensure no less than 75% of children diagnosed with permanent hearing loss are enrolled in early intervention services before age 6 months	● 95% of families will receive a toolkit within 4 weeks of diagnosis notification ● 95% of families will be contacted by phone within 4 weeks of diagnosis notification ● 100% of families opting into GBYS will be contacted by a Parent Guide within 3 days of enrollment date
Objectives	**Activities/Steps**
A) Within 4 weeks of receiving confirmation of diagnosed hearing loss, the EHDI program will contact by letter, phone or video phone (reached or not reached) 95% of families with newly diagnosed children	1) Families will receive info in EHDI Parent Toolkit 2) Family contact will be attempted by phone within four weeks of confirmation of loss 3) GBYS follow-up letter will be sent if not able to connect with family via phone 4) If reached, services will be discussed and family will be offered GBYS 5) GBYS assists family in connecting with Early Intervention if this has not yet occurred **Program Staff Responsible:** EHDI Follow-up Coordinator, EHDI Program Specialist, GBYS Program Coordinator

Objectives	Activities/Steps
B) By March 2015, 90% of babies who develop hearing loss or who are found to have permanent hearing loss after six months of age will be enrolled in early intervention by three months post diagnosis.	1) Families will receive info in EHDI Parent Toolkit which will continue to include materials about Maternal & Children Health, Part C Early Intervention, Children with Special Health Care Needs, family support organizations, and other health and social support services 2) Family contact will be attempted by phone within four weeks of confirmation of loss 3) GBYS follow-up letter will be sent if not able to connect with family via phone 4) If reached, services will be discussed and family will be offered GBYS 5) GBYS assists family in connecting with Early Intervention if this has not yet occurred **Program Staff Responsible:** EHDI Follow-up Coordinator, EHDI Program Specialist, GBYS Program Coordinator
C) By March 2015, hearing technology status will be reported to the EHDI program on 95% of the children identified annually with hearing loss whose families are enrolled in GBYS.	1) Families will be queried about current status and any plans related to amplification [in a culturally-sensitive, family-focused manner] 2) Results will note status in EARS Outcomes Form **Program Staff Responsible:** GBYS Program Coordinator, GBYS Parent Guides
Goal 4	**Measures of Success**
The EHDI program will expand awareness and education about EHDI among primary care providers (PCP)/Medical Homes, Ear, Nose, & Throat (ENT) Specialists to enhance "1-3-6" as a Standard of Care and to ensure that appropriate medical care and intervention/education services are provided to children enrolled in their practice	● 95% of letters sent to PCP about children not passing UNHS will be sent within one month of notification ● 95% of letters sent to PCP about children diagnosed with hearing loss will be sent within one month of notification to EHDI program ● By May 2012, 3-year PCP plan will be completed ● ENT Care plan will be distributed to at least 20 ENT practices

Objectives	Activities/Steps
A) By March 2015, 95% of Primary Care Providers will be contacted by the EHDI program within one month of notification that a child did not pass newborn hearing screening	1) Per current practice, the EHDI program will mail a copy of the parent F/U letter sent to the PCP and include a fax-back/mail-back form that can be used to share results with EHDI **Program Staff Responsible:** EHDI Parent Consultant
B) By March 2015, 95% of Primary Care Providers will be contacted by the EHDI program when a child at risk for delayed onset of hearing loss is approximately 7 months of age and is in need of follow-up testing between 9 and 12 months of age.	1) Per current practice, birthing facilities notify the PCP of passed at risk status. The EHDI program send the PCP a copy of the parent's reminder letter at 7 months of age (that baby needs diag eval at 9-12 mos of age) which includes a fax-back/mail-back form that can be used to share results with EHDI **Program Staff Responsible:** EHDI program support staff
C) By March 2015, Primary Care Provider Toolkits will be provided to the individual providers of 95% of children identified with permanent hearing loss.	1) Letters of notification and toolkit materials will be mailed to child's PCP upon confirmed diagnosis of hearing loss **Program Staff Responsible:** EHDI Follow-up Coordinator, GBYS Parent Program Coordinator
D) By June 2013, PCPs will be provided with a summary of the Joint Committee on Infant Hearing (JCIH) Early Intervention supplement (to be released in 2011) to improve awareness of intervention recommendations for children identified with hearing loss.	1) Will share info as part of presentations conducted for physicians at least once annually (upon availability of the document) 2) An electronic version will be placed at www.hearing.IN.gov and emailed to our list of physicians **Program Staff Responsible:** EHDI Director, AAP EHDI Chapter Champion, IT Staff

Objectives	Activities/Steps
D) By May 2012, in coordination with the IN AAP Chapter Champion, a 3- year plan to educate PCPs will be developed and implemented to improve awareness of newborn hearing screening follow-up recommendations, implications for delayed diagnosis of hearing loss, medical assessments, and interventions for children with diagnosed hearing loss.	1) 3 year plan for education of PCPs across the state will be developed 2) Educational materials and methods of integrating the medical home into follow-up care will be developed 3) A fact sheet for ENTs will be developed **Program Staff Responsible:** EHDI Director, AAP EHDI Chapter Champion
E) By June 2013, a ENT EHDI Care Plan will be developed and disseminated to ENT physicians across Indiana	1) An ENT Care Plan was developed by our NICHQ team and will be assessed for any changes that might be needed 2) The ENT Care Plan will be disseminated via email and placed at www.hearing.IN.gov **Program Staff Responsible:** EHDI Director, AAP EHDI Chapter Champion, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants, EHDI Advisory Committee, NICHQ team
Goal 5	**Measures of Success**
The EHDI program will expand awareness and education among parents about EHDI goals, resources, and formal family support programming through collaborative work with Maternal Infant Early Childhood Home Visiting programs (specifically, Healthy Families Indiana [HFI] and Nurse Family Partnerships [NFP]), the Early Childhood Comprehensive System (a.k.a. Sunny Start) and Indiana Hands & Voices	● At least two webinars are held annually by EHDI for HFI, NFP, and Sunny Start ● At least two webinars are held annually for birthing facility personnel, audiologists, primary care providers, and early interventionists to share HFI, NFP and Sunny Start information ● By April 2015, 90% of children enrolled in GBYS will have IFSP, hearing technology, communication, and early intervention services documented in EARS ● By November 2012, two new EHDI Advisory Committee members will be added that represent one parent, one Deaf or Hard of Hearing college student or young adult

Objectives	Activities/Steps
A) Beginning June 2012, EHDI will increase awareness of Early Hearing Detection & Intervention (EHDI) among Healthy Families Indiana (HFI) and Nurse-Family Partnerships (NFP) Home Visitors and families by providing at least two webinars annually about EHDI related topics	1) EHDI will design a training for HFI and NFP Home Visitors 2) Trainings will be conducted and resources provided for staff on newborn hearing screening, signs of hearing loss, impact of hearing loss, communication development and appropriate referral mechanisms, IN Hands & Voices, GBYS, and the Statewide Referral Network for Deaf and Hard of Hearing Children 3) A set of questions will be developed and introduced that HFI and NFP Home Visitors can use with families to reduce loss to follow-up **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator
B) Beginning June 2012, EHDI will increase awareness of Early Hearing Detection & Intervention (EHDI) among Sunny Start Core Partners (who represent public and private entities and parents of children with special healthcare needs by providing presentations at Sunny Start Core Partner meetings during Years 1 and 3.	1) Continue EHDI participation as a Sunny Start Core Partner 2) Conduct presentations at Sunny Start Core Partners meetings in Year 1 and 3 of the grant **Program Staff Responsible:** EHDI Director
C) Beginning June 2012, EHDI will increase awareness of Sunny Start resources among birthing facility personnel, audiologists, primary care providers, and early interventionists as they participate in the Early Hearing Detection and Intervention (EHDI) process by conducting at least two webinars annually	1) Provide the Early Childhood Meeting Place link for easy access to resources such as the Family Resource Fact Sheets and the Wellness Passport for Indiana's Kids to a) Indiana birthing facilities, b) audiologists, c) primary care providers, and d) early interventionists to share with families at appointments or home visits **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, GBYS Coordinator and Parent Guides

Objectives	Activities/Steps
D) Beginning June 2012, EHDI will increase awareness of Sunny Start resources among families as they participate in the Early Hearing Detection and Intervention (EHDI) process by including materials in 100% of the EHDI Parent Toolkits provided	1) Provide selected Sunny Start resources (i.e. financial) to families of newly diagnosed children in the EHDI Parent Toolkit to enhance likelihood of appropriate follow-up **Program Staff Responsible:** EHDI Follow-up Coordinator, EHDI Program Specialist and EHDI Parent Consultant, GBYS Program Coordinator and Parent Guides
E) By March 2015, Individualized Family Service Plan (IFSP) recommendations will be received by EHDI for 90% of children whose families are enrolled in GBYS	1) Families will be asked to sign a Universal Release form that will allow for sharing of IFSP info with EHDI 2) Release will be scanned and uploaded into EARS **Program Staff Responsible:** GBYS Program Coordinator and Parent Guides
F) By March 2015, hearing technology status will be known for 90% of children whose families are enrolled in GBYS	1) Families will be asked for information related to their child's hearing technology status 2) Info will be reported in EARS **Program Staff Responsible:** GBYS Program Coordinator and Parent Guides
G) By March 2015, child-centric information will be known related to the specific types of early intervention services provided for no less than 90% of children enrolled in GBYS	1) IFSP or GBYS Parent Guide data will be viewed to determine services child is receiving and documented on EARS Outcomes Form **Program Staff Responsible:** EHDI Follow-up Coordinator, GBYS Program Coordinator, and GBYS Parent Guides

Objectives	Activities/Steps
H) By March 2015, early communication option(s) selections will be known for 90% of children diagnosed with hearing loss enrolled in GBYS so that families may be supported in their decisions and pursuit of appropriate services	1) In a culturally-sensitive, family-centered manner, families will be queried during post-diagnosis phone call and during GBYS parent-to-parent support contacts about any decisions they have made related to communication mode or methodology 2) This data will be documented on EARS Outcomes Form **Program Staff Responsible:** GBYS Program Coordinator and Parent Guides
I) By April 2015, Indiana Hands & Voices will have planned, implemented and evaluated three annual EHDI Family Conferences for families of children diagnosed with hearing loss ages birth to six years	1) Convene annual planning committee and subcommittees 2) Plan culturally-sensitive family-centered conference 3) Promote, Conduct and Evaluate and 4) Report results to EHDI **Program Staff Responsible:** GBYS Program Coordinator, H&V Family Outreach Coordinator, and H & V Executive Director
J) By November 2012, the EHDI program will compensate family members, youth and consumers who are members of the EHDI Advisory Committee and are not paid to participate by another entity	1) Bring a recommendation of adding two new members (one parent, one Deaf or Hard of Hearing college student or young adult) to the EHDI Advisory Committee 2) If approved, identify candidates 3) Invite to participate and compensate for participation **Program Staff Responsible:** EHDI Director, H & V Executive Director

Goal 6	Measures of Success
Communicate with families through social (marketing) media tools to 1) encourage parents to "pay attention" to their baby's hearing and communication efforts and 2) to locate resources and support if their child is diagnosed with hearing loss	● By April 2012, monthly Face Book posts, tweets, and e-newsletters will be completed ● By Sept 2012, a plan for sharing Loss & Found video with Indiana high schools will be developed and implemented
Objectives	**Activities/Steps**
A) Beginning April 2012, the EHDI program will post EHDI-related information that is of interest to EHDI stakeholders on Face Book and Twitter once monthly.	1) Face Book posts will be developed 2) Information will be posted on the Indiana Hands & Voices (IN H&V) Face Book and tweet will be sent via the IN H&V Twitter account **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, GBYS Coordinator, IN H & V Executive Director
B) By Sept 2012, a plan will be created with the Indiana Department of Education to enable access to the Loss & Found DVD as an educational tool to high school students and educators and a method for increasing awareness about hearing and reducing lost to follow-up	1) Meet with the IN Dept of Ed Health Services Director 2) Identify possible venues to show the Loss & Found DVD 3) Plan and implement the use of the Loss & Found DVD in appropriate high school settings **Program Staff Responsible:** EHDI Director, GBYS Coordinator, IN H&V Executive Director
C) By September 2012, Indiana Hands & Voices will provide a monthly E-letter to all current GBYS families, past GBYS families, and the professionals that serve them to ensure that families and professionals are up to date on family support activities around the state.	1) Design newsletter 2) Send for review to IN H&V Executive Director and GBYS Coordinator 3) Send out quarterly newsletter beginning Sept 2012 **Program Staff Responsible:** EHDI Director, GBYS Coordinator, IN H&V Executive Director, IN H&V Outreach Director

Goal 7	Measures of Success
Enhance data quality, collection and management to improve tracking and surveillance through the EHDI Alert Response System (EARS)	● By December 2013, duplicate records will be less than 10% of records in EARS ● 98% of hospitals will use EARS ● By December 2013, 95% of DAE forms will be submitted electronically
Objectives	**Activities/Steps**
A) By December 2013, the proportion of duplicate files will be reduced to less than 10% so that valid and verifiable data is provided from all reporting sources on children so that EARS and EHDI staff are able to identify, match, collect and report unduplicated and individually identifiable data on all Indiana occurrent births	1) Develop program protocols for account monitoring and organization management 2) Fully implement current Data Audit Tool with all facilities to identify duplicate records 3) Develop Data Management Tool for dealing with duplicate records easily and quickly 4) Merging of duplicate records **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, IT staff, and UNHS Nurse Coordinator
B) On an ongoing basis, the EHDI program will work the Genomics & Newborn Screening program to leverage Integrated Technology innovations and public health informatics solutions that serve EHDI stakeholders and particularly EARS users by participating in four meetings per year about public health informatics	1) Continue to participate in meetings of stakeholders and Health Information Exchange Organizations 2) Apply knowledge gained, as appropriate, to integrated data system plans **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator
C) On an ongoing basis, 98% of Indiana birthing facilities will report babies to EHDI using the EARS system so that data quality and integrity will be enhanced	1) Provide technical assistance as needed to birthing facilities 2) Provide one-on-one training to new facility staff who report in EARS 3) Offer webinar trainings four times annually 4) Conduct face-to-face visits annually with 5 to 10% of birthing facilities (visits reserved for those most in need) **Program Staff Responsible:** EHDI Follow-up Coordinator, EARS Specialist, Regional Audiology Consultants

Objectives	Activities/Steps
D) By December 2013, 95% of DAE forms submitted by audiologists evaluating children will be electronically via the Diagnostic Audiology Evaluation (DAE) section of EARS web-based data system	1) Provide annual EARS trainings 2) Quarterly, send EHDI-grams to audiologists to provide training, announcement and program updates **Program Staff Responsible:** EHDI Follow-up Coordinator, EARS Specialists, Regional Audiology Consultants
Goal 8	**Measures of Success**
Contribute to infrastructure development through core public health assessment, policy development and assurance functions	● State of EHDI report is developed by May 2012 ● At least two opportunities for improvement within the larger EHDI system are identified and plans developed to address the issues
Objectives	**Activities/Steps**
A) On an annual basis (May 2012, 2013, 2014) inform and educate the public and families about the EHDI program, its statistic, and progress, and "hot issues" through a "State of EHDI" document	1) November 2011create document plan including content 2) February 2012, data will be pulled 3) March 2012 first draft to be completed 4) April 2012 final document review 5) May 2012 document to be sent out via email and post to www.hearing.IN.gov **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EARS Specialist
B) On an ongoing basis, EHDI will participate in at least one quarterly Maternal & Child Health and non-Maternal & Child Health community collaborations and partnerships to identify and solve EHDI problems.	1) Participate in quarterly Sunny Start meetings 2) Participate in monthly Life Course planning meetings 3) At least two State Part C meetings annually **Program Staff Responsible:** EHDI Director

Objectives	Activities/Steps
C) By June 2012, plans will be developed and implemented to improve the capacity and competency of the public health and personal health workforce, as well as, the Part C early intervention and Part B education workforces to effectively and efficiently address the needs of children with hearing loss by providing technical support, trainings and dissemination of materials to Indiana professionals.	1) Develop a two-year plan with Karen Goehl (who has offered to share funding for activities through the PASS project) for professional development of the EHDI, Part C and Part B workforce that provides services or wishes to provide services to children with hearing loss 2) Develop a plan to target a minimum of six audiology practices in need of support and education to either develop or improve follow-up evaluation capacity and streamline recommendations to be consistent with "Indiana's Best Practices in Audiology" document **Program Staff Responsible:** EHDI Director, Regional Audiology Consultants, GBYS Program Coordinator, EHDI Follow-up Coordinator
D) By July 2012, EHDI and the State Head Start Collaboration Office will evaluate data obtained the Early Childhood Hearing Outreach (ECHO) and determine the feasibility of statewide spread through Indiana Early Head Start Programs.	1) By July 2012, the EHDI program will conclude its involvement in the Early Childhood Hearing Outreach (ECHO) pilot project that is currently underway with three Indiana Early Head Start programs 2) By June 2012, the EHDI program will evaluate the feasibility and make recommendations related to statewide spread of the Early Childhood Hearing Outreach (ECHO) with Indiana Early Head Start Programs. **Program Staff Responsible:** EHDI Director

Objectives	Activities/Steps
E) By September 2012, EHDI will improve access to integrated community systems of care for children and their families across the EHDI process by identifying and implementing at least two quality improvement measures.	1) By Sept 2012, develop a Universal Release of Information form to enhance sharing of information among agencies that participate in the EHDI process 2) By Sept 2012, at least two quality improvement projects will be identified and a plan to address them created and implemented 3) Provision of two First Steps forums to ensure that audiologists and early intervention personnel understand and communicate to families the purpose and flow of EHDI. **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, Regional Audiology Consultants
F) By March 2014, a plan will be developed to promote sustainability of the program aspects for which funding is being requested in this grant opportunity through the Maternal & Child Health Bureau.	1) With Indiana Hands & Voices, by March 2014, develop a written sustainability plan **Program Staff Responsible:** EHDI Director, Indiana Hands & Voices Executive Director, GBYS Coordinator
Goal 9	**Measures of Success**
Conduct program evaluation activities to ensure that the Indiana EHDI program is achieving "1-3-6" and its other goals and objectives that lead to success for children with hearing loss	● By September 2012, survey template will be available to assist with identifying areas of concern with hospitals UNHS programs ● By January 2013 survey results will be available ● By February 2013 at least two quality improvement activities will be planned, studied and implemented

Objectives	Activities/Steps
A) By September 2012, ISDH EHDI will collaborate with reporting sources by providing EARS training, feedback and performance metrics on at least an annual basis.	1) A performance improvement template will be developed for use with birthing facilities with issues related to screening rates, referral rates, and scheduling of follow-up appointments prior to hospital discharge for infants not passing UNHS **Program Staff Responsible:** EHDI Director, Regional Audiology Consultants, EHDI follow-up Coordinator, EHDI Program Specialist
B) By September 2012, a formal program evaluation plan will be developed that includes at least one hospital survey, one audiologist survey, and one survey for parents	1) EHDI Advisory Committee will receive draft of evaluation plan and given an opportunity to provide input 2) Develop a plan and timeline to conduct a comprehensive evaluation 3) Surveys will be created and sent out based on the developed plan 4) Surveys will be returned and data analyzed 5) EHDI Staff will discuss results, next steps, and quality improvement modifications that are needed **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EARS Program Specialist, Regional Audiology Consultants, GBYS Program Coordinator, Indiana Hands & Voices Executive Director, IN H&V Outreach Director

Objectives	Activities/Steps
C) Quarterly, EHDI will run data reports on all "Measures of Success" to monitor progress on program goals and objectives	1) Analysis of "Measures of Success" will be used to conduct quantitative assessment of data items and to answer normative and causative questions (as discussed in Program Evaluation section) 2) Data will be shared with program staff and stakeholders at EHDI Advisory Committee meetings 3) Data will be evaluated to inform EHDI of need for course corrections and new directions 4) Data will be reported in grant progress reports 5) Statistics will be made available to the public in presentations on the website **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, IT Staff, Epidemiologist

Table 6: Work Plan

RESOLUTION OF CHALLENGES

Reducing Indiana's loss to follow-up in babies who do not pass newborn hearing screening as discussed in the Needs section and as outlined in the Work Plan can be effectively done provided that certain challenges are overcome. This section will discuss challenges that are likely to be encountered in implementing activities listed in the Work Plan and strategies for resolving those challenges

A primary challenge in addressing reduction in loss to follow-up is ensuring that activities that directly impact loss to follow-up are conducted in a timely manner. Through its highly qualified staff, access to a quality data system, support from ISDH administration, Maternal and Child Health community, and EHDI system of providers/stakeholders, the EHDI program has been improving. EHDI is able to document continual improvements in timeliness, numbers of families reached, and feedback from families that EHDI's involvement in the EHDI process is highly important in ensuring that the system and services is available to them. Key to ongoing improvement and resolution of challenges is EHDI's ability to secure and maintain sufficient and appropriate staff to ensure that the EHDI process is successful for as many families as possible. The EHDI program seeks to receive grant funding from the Health Resources & Services Administration to support the hiring of a part-time EHDI Program Specialist, continuing a contractual relationship with Indiana Hands & Voices for two EHDI Parent Consultants, the Guide by Your Side program, the annual Indiana EHDI Family Conference, and the new position of GBYS Family Outreach Coordinator.

Challenges to completing some of the activities in the Work Plan and resolution of those challenges are included in Table 8.

Challenge	**Resolution**
Implementing reporting of all babies' screening results directly from birthing facility equipment	Work with a vendor and a representative group birthing facilities to determine a plan that will work for the majority of facilities
Completing follow-up activities in a timely manner to ensure screening, diagnostic audiology follow-up and enrollment in early intervention for all families as appropriate	Retain EHDI Parent Consultant positions, the GBYS program, and hiring of a part-time EHDI Program Specialist
Reciprocal sharing of child-centric information with the EHDI program so that children may be effectively tracked	Work with State agencies, private entities and audiologist involved in the EHDI process to develop a Universal Reciprocal Release and work with the new Statewide Resource Network for Deaf and Hard of Hearing Children (which contracts with Part C) to ensure that all children are known to "the system"
Education of all physicians in supporting hearing screening results, immediate follow-up after failure to pass newborn screening, and participation in etiology activities	Work with the EHDI Chapter Champion in implementation of a 3-year plan to impact primary care provider and otolaryngologist knowledge set, orientation and practice
Successfully reaching high school students to increase awareness about EHDI	Work with the Department of Education to provide the Loss & Found DVD as an educational tool in one or more high school venues (i.e. child development and health classes, technical school daycares, career-related classes)
Implementing a training plan for audiologists and Part C and Part B personnel	Work with the PASS project, IN Hands & Voices, and a small group of stakeholders to pool resources for training
Implementing state wide spread of hearing screening in Early Head Start	Work with Head Start Collaboration Office and the EHDI Regional Audiology Network to create and implement a plan that works for both programs and Early Head Start program without over stretching EHDI's resources
Securing sufficient time for quality improvement program evaluation activities	Re-distribute some of the EHDI Follow-up Coordinator's work to a yet to be hired EHDI Program Specialist

Table 8: Challenges and Resolutions

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Specific attention was given to creating goals and objectives on the Work Plan that would be measurable and for which data would be available and retrievable in the EARS system. The goals and objectives in the Work Plan will be evaluated based on actual program outcomes. Quarterly data pulls and survey results will permit the EHDI program to evaluate progress and program effectiveness and assist in determining if planned activities are having the intended results and outcomes. Successful achievement of program outcomes can be ascertained from data and by addressing two specific types of questions: normative questions and causal questions.

Three normative questions that address the impact of EHDI and will be used as part of program evaluation include: 1) "Does EHDI provide the services that are intended to achieve the objectives of the program?" 2) "Does EHDI successfully deliver services to the target population?" and 3) Are the outcomes of program participation intended by the EHDI program/system/process?"

To answer the first question, program evaluation activities will determine to what extent the EHDI system is delivering intended services to families. The second question relates to implementation of EHDI services provided across the state. This question is answered by determining whether the families served are those that EHDI intended to serve and whether the environment (i.e. infrastructure, population, enabling and direct services) that exists in Indiana is "a fit" with what children and their families need (at the State, regional and local levels). The implementation of programming is important, but only in so far that the processes and activities employed to reach EHDI's intended outcomes actually achieve the expected results as outlined in the Work Plan goals and objectives. The third questions relates to whether the intended outcomes of the EHDI Work Plan are achieved for individual families and, if so or not, what, if any, unintended negative consequences occur for families and the rest of the EHDI stakeholder community. Each of these three questions will be asked as part of evaluation of quarterly data.

Causal or descriptive questions will also be used to assist the EHDI program in determining why certain results did or did not happen as intended and outlined in the Work Plan. Causal questions extend beyond normative questions in that normative questions help establish whether EHDI program delivered on its intended outcomes, while causal questions ask "why did the intended results happen or not happen" and "should we keep doing what we're doing or change something?" Also, "is what we're doing beneficial to families and should we do more or less of it?" The EHDI program in Indiana has a staff who is very familiar with the systems and services families use and while the program sometimes uses intuition or "a hunch" to determine why certain results have occurred, the program is committed to conducting regular program evaluation and quality improvement activities to quantify and qualify both the "what" and "why" of our results and outcomes.

The technical capacity of ISDH to implement and evaluate EHDI in Indiana is strong in that the EHDI program has a highly capable staff. The EHDI Program Director is an audiologist and speech-language pathologist who provided direct services for sixteen years prior to moving into program administration roles (Chief Programs Officer for a non-profit organization devoted to individuals with hearing loss and Indiana EHDI Program Director). The EHDI Follow-up Coordinator is an audiologist who has provided direct services, worked in the Part C and private service systems, and has been a member of a well-established research team which provided her

with extensive experience in working with and analyzing data. The Guide By Your Side Program Coordinator is the parent of a child with hearing loss, has had extensive advocacy training and experience, has worked as a district manager of a large department store chain where she provided extensive staff training and evaluation, and is the current director of the national Guide By Your Side program for national Hands & Voices. The EHDI program has access to the Genomics and Newborn Screening epidemiologist and to a team of Information Technology professionals, one of whom is assigned to the EHDI program part time. The EHDI staff with support from epidemiology and information technology staff will be able to obtain and analyze data from EARS and program surveys to adequately evaluate the EHDI program on a regular basis. EHDI staff will use this data in grant progress report, in presentations and in published articles to reflect Indiana's performance and progress during this grant period.

ORGANIZATIONAL INFORMATION (and Staffing Plan)

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.

Reporting of data on children who are involved in the EHDI process is an important aspect of ensuring that early detection of hearing loss and early intention occur and Indiana's newborn screening law supports the work being conducted by 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. (2) 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). Physicians 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 is entered into EARS or faxed to ISDH.

EHDI staff has prepared an ambitious Work Plan for the next three years that will be administered through the EHDI program and delivered across the state through providers

involved in EHDI. An organization chart of the EHDI program is provided as Attachment 5. EHDI staff includes:

EHDI Staff	Hours per Week	Person	Primary Responsibilities
EHDI Program Director	34	Gayla Hutsell Guignard	Program oversight, administration, management and supervision, internal and external relationships and direction for reduction of loss to follow-up and improvement of the EHDI process, system and program
EHDI Follow-up Coordinator	32	Julie Schulte	Oversight and conduction of EHDI follow-up activities for screening, diagnosis and intervention, monitoring of Parent Consultants, EARS data activities for grants, reports, quality improvement, and EARS system program troubleshooting, provision of technical assistance and training
EHDI Program Specialist (to be hired)	16	TBD	Conduction of EHDI follow-up activities and EARS technical assistance and training under the direction of the EHDI F/U Coordinator
EHDI Parent Consultant (bilingual)	20	Julie Swaim	EHDI follow-up activities (i.e. phone calls, letters, documentation, EARS alert processing) involving babies who do not pass newborn hearing screening and contacting families of children diagnosed

			with hearing loss whose language of the home is Spanish
EHDI Parent Consultant (in process of hiring)	16	TBD	EHDI follow-up activities (i.e. phone calls, letters, documentation, EARS alert processing) involving babies who do not pass newborn hearing screening
GBYS Program Coordinator • 10 GBYS Parent Guides-up to 15 hours monthly	24	Lisa Kovacs	EHDI follow-up activities with families of children diagnosed with hearing loss and GBYS program oversight, administration, management, and supervision
EHDI Regional Audiology Consultant Lead • 7 Regional Audiology Consultants-10-20 hours monthly	8	Molly Pope	Oversight of Regional Audiology Consultant activities across the state and and conduction of hospital technical assistance and activities for the Central Indiana Region
EHDI Clerical Staff	37	Maricela Porras	Administrative duties related to EARS letters, EHDI program activities and meeting support

Table 9: EHDI staff titles, hours worked, and responsibilities

The EHDI program team is well-coordinated and effective in conducting daily and other activities that reduce loss to follow-up.

An EHDI Governor's Task Force was established in 1999 to assist ISDH in the creation of an EHDI program in Indiana. That task force has developed into an EHDI Advisory Committee. The EHDI Advisory Committee, which consistent of 14 members, who represent the various groups of EHDI stakeholder, are committed to improving Indiana's EHDI system and reducing loss to follow-up for all children. The advisory committee meets quarterly to advise the EHDI program on pertinent issues to the work that is being conducted across the state and to receive updates related to program evaluation (including data) and grant activities. This committee has also worked on special projects such as tele-intervention and outreach to primary care providers.

At the State and local levels, the EHDI program is receptive to working with all stakeholders interested in positively impacting EHDI, education and health for children in Indiana. Ongoing communication and activity exists between EHDI program staff and individuals, groups, agencies and organizations interested in the welfare of children with hearing loss, some of which has been outlined in the Needs and Work Plan sections of this narrative.

Indiana incorporates Federal and national resources into its programming by including information that is provided through the Centers for Disease Control (CDC), the National Center on Hearing Assessment and Management (NCHAM), and the American Speech-Language-Hearing Association (ASHA). Additionally, Indiana's EHDI Program Director serves as the Region V representative for NCHAM, a relationship that adds to Indiana's relationship with other states in the Midwest region as well as across the country.

ISDH and its EHDI program is pleased to submit this grant application on behalf of the State of Indiana. If funded, the EHDI program will work with the systems and services across the state that serve children and families, the EHDI Advisory committee and myriad of stakeholders to achieve the intended outcomes of this application.

Project Identifier Information:
Grant Number: H61MC23640

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

Organization: Indiana State Department of Health, 2 North Meridian, Section 7F, Indianapolis, IN 46204

Project Director: Gayla Hutsell Guignard, M.A., CCC-A/SLP, Cert AVT, Center for Deaf and Hard of Hearing Education Director, 317-232-5950 (phone), 317-550-4873 (fax), ghutsell@isdh.IN.gov (email)

Primary Contact Person: Julie R Schulte, M.A., CCC-A, Interim EHDI Program Director and EHDI Follow-up Coordinator, 317-233-1264 (phone), 317-925-2888 (fax), juschulte@isdh.in.gov (email)

Accomplishments and Barriers:

The Indiana Early Hearing Detection and Intervention (EHDI) program has undergone significant change over the last year. Indiana Governor Mitch Daniels signed House Bill 1367 in March 2012 which established the Center for Deaf and Hard of Hearing Education (CDHHE). The CDHHE was created to improve services for children with hearing loss from birth to 21 years of age and to assume responsibility for statewide outreach and educational consulting which was previously under the umbrella of the Indiana School for the Deaf. Under the guidance of the Indiana Office of Budget and Management a stakeholder group was established and a transition plan was created. On October 1, 2012 the transition plan was submitted to the Indiana General Assembly for review and consideration. Additional recommendations that are pertinent to EHDI include placing the CDHHE organizationally at the Division level under the Indiana State Department of Health, moving the EHDI program under the auspices of the CDHHE, expanding family support programming and expanding follow-up activities to include children/students from newborn screening through school exit. In early 2013 a State budget was passed which included funds for the CDHHE. By June 2013, Gayla Hutsell Guignard (former EHDI Program Director) was hired as the Director of the Center for Deaf and Hard of Hearing Education and Julie Schulte resumed her role as the Interim EHDI program director.

While the physical location of the EHDI program has changed, the primary programmatic goals and objectives of the EHDI program remain the same. The primary purpose continues to be to ensure early identification and early intervention for children with permanent hearing loss through reduction of loss to follow-up and facilitation of the EHDI process (screening, identification, family support, and intervention). In order to effectively implement services, Indiana EHDI provides formal family support programming through Indiana Hands & Voices and its Guide By Your Side (GBYS) program. The Indiana EHDI program works individually and collectively with parents and birthing facilities, medical offices, audiologists and early intervention personnel to ensure that screening, identification and early intervention all occur in a timely manner. Targeted efforts are consistently made towards screening all Indiana babies by one month of age, confirming hearing status on babies who do not pass newborn hearing screening before three months of age, and enrollment in early intervention by six months of age for those children with permanent hearing loss.

Significant accomplishments for the EHDI program during this reporting period include:

1) The Interim EHDI Program Director attended the close-out meeting for the Centers for Disease Control and Prevention's iEHDI project. Indiana was one of three states to participate in this project that developed a common set of data items and definitions that were used across all three states. Once the data dictionary was completed, each state sent to the CDC in a common format child-centric, de-identified data for all children born during a given time period. Data was sent quarterly from each state for babies born in 2010. The CDC staff was able to use the data to complete in-depth analysis to describe demographics of children screened, those diagnosed with permanent hearing loss and those considered lost to follow-up. This in-depth analysis was shared during the close-out meeting and additional plans were made to continue on with this work.
2) The Indiana EHDI program and the Minnesota EHDI program began a pilot study in January 2014 under the guidance of the CDC to look at the feasibility of EHDI programs collecting early intervention information beyond basic enrollment information. A procedure for obtaining data items from parents of identified children is in place.
3) Guide By Your Side (GBYS) Health Assessment was established by Hands & Voices Headquarters in 2013 to measure the "health" of individual GBYS programs. These indicators are all important elements to ensure success and compliance operating a GBYS program. This required GBYS Health Assessment will now be done annually with proposed program goals based on areas of the health assessment that need to be improved or addressed. Indiana GBYS participated in this Health Assessment and will begin targeting areas in need in early 2014.
4) The Leveled Recognition Program was established by Hands & Voices Headquarters in 2013 to ensure that GBYS Parent Guides (and deaf and hard of hearing guides not applicable in Indiana) have all received the required initial training as well as providing the opportunity to show professional growth through baseline competencies at three different levels. This program requires a minimum number of activity points per each guide each year to ensure Parent Guides are actively engaged in their local programs. It also establishes a required annual self-evaluation for all Guides and Program Coordinators. Indiana GBYS began implementation of this Leveled Recognition Program in the 4th quarter of 2013 and will continue its implementation as trainings for new and continuing guides are planned.

Challenges/Barriers:

1) With the establishment and opening of the Center for Deaf and Hard of Hearing Education and the subsequent move of the EHDI program and Guide By Your Side to a new location there has been staff changes, as well as some delays, in ongoing programmatic development. Examples of delays will be discussed in the goals and objectives section of this report. Gayla Hutsell Guignard, the previous EHDI Program Director, was hired as the Director of the CDHHE. Julie Schulte the EHDI Follow-up Coordinator has taken on the role of the Interim EHDI Program Director until a new director can be hired. The job announcement has been released and it is anticipated that a new EHDI Program Director will be hired in the first quarter of 2014.
2) As discussed in previous reports, obtaining early intervention information for children diagnosed with permanent hearing loss is somewhat limited and the information currently obtained is labor intensive to obtain. Over the last year, the EHDI staff has increased the number of children with signed releases and IFPSs on file; however considerable improvement is still needed. With the establishment of the CDHHE, modifications to EHDI

protocols and those followed by CDHHE early intervention staff are underway and will be piloted in early 2014 to improve the quantity and quality of early intervention data being obtained.

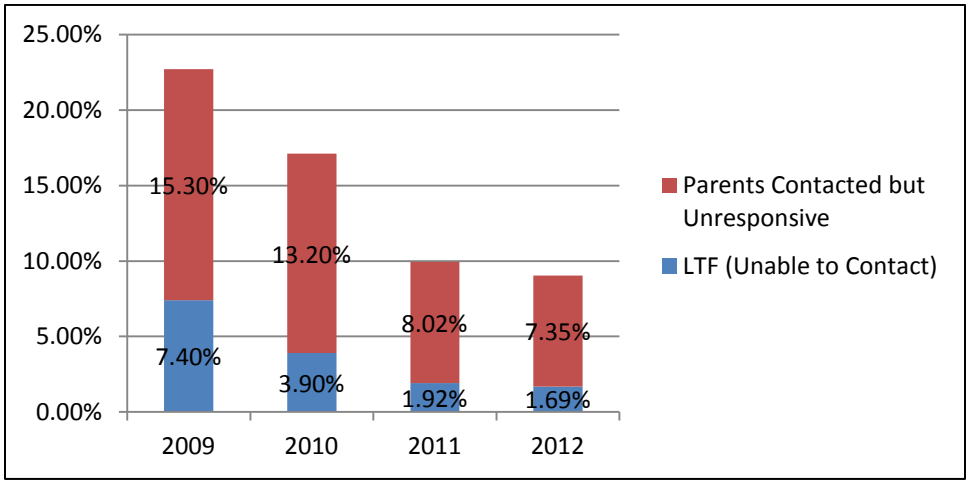
Goals and Objectives:
Indiana's progress on goals outlined in the original application is as follows:
Goal 1: The Indiana EHDI system will work collaboratively to ensure that 97% of babies receive newborn hearing screening before age one month. **Objective: A)** By Jan 2014, screening results will be received by the EHDI program on all children screened at all birthing facilities. **Status:** Preliminary screening rate for children born in 2012 is 97.57% with 88.8% of babies passing before one month of age. **B)** By Oct 2012, capacity for screening by midwife personnel will increase by adding loaner screening equipment to at least three midwifery practices that are currently not screening newborns**. Status:** In progress. **C**) By Sept 2012 EHDI will design updated hospital training and provide at least 4 webinars annually **Status: Met** with change in objective. The Indiana EHDI program adopted the use of the NCHAM Newborn Hearing Screening Training Curriculum in July 2012 as a method to provide basic training for birthing facility personnel involved in the screening process. EHDI now requires that all new hospital staff submitting reports must complete the NCHAM training and complete a power point based training that discusses reporting requirements. Since January 2013, 149 hospital staff from 62 different Indiana hospitals have taken the NCHAM training. Hospitals that have not taken the training will be targeting for face to face training by the Indiana Regional Audiology Consultant network. **D)** By March 2016, 98% of birthing facilities will use EHDI- designed materials with parents that emphasize the importance of UNHS and follow-up. **Status: Met**

Goal 2) The Indiana EHDI system will work collaboratively to ensure that no less than 75% of babies who do not pass newborn hearing screening receive confirmatory diagnosis of hearing status before age 3 months. Objective A) Annually, the EHDI program will attempt to contact 100% of families of babies who do not pass newborn hearing screening and are reported to the EHDI program and who have not yet received diagnostic follow-up will be contacted by the EHDI program within one month of notification in the EHDI EARS system. **Status:** For babies born in 2012 the EHDI Parent Consultants attempted to contact every family if a diagnostic audiology evaluation (DAE) form was not on file. Data from this time period indicates that 82.78% of families were contacted by EHDI via phone and mail but only 58.9% were contacted within one month of the EHDI program being notified that the child did not pass UNHS. For the first half of 2013, 85.45% of families were contacted via phone and letter with 61.76% being contacted within 30 days of being reported to the EHDI program as not passing UNHS. It is noted that some families may not have been contacted within 30 days because 1) their child received a diagnostic evaluation within that 30 day period that supported normal hearing or 2) their child remained in the NICU and per Indiana protocols families are not contacted until babies are discharged from the hospital. **B)** By March 2015, when diagnostic results are not received for children who do not pass newborn hearing screening by the EHDI program within 75 days of initial EHDI program contact, the EHDI program will attempt to re-contact no less than 100% of the remaining families by phone and letter. **Status:** This data is not yet available. Development of queries and reports were tested over the last year but the current data collected by EARS does not enable calculating of this information readily. Modifications to dates captured in EARS are under to discussion to enable closer review of this information. **C)**

By March 2015, 75% of Indiana non-NICU babies not passing UNHS will receive a confirmatory diagnosis by 3 months of age. **Status:** Preliminary data for children born in 2012 indicates that 66.4% of the children who did not pass the hearing screening received confirmation of hearing status by 3 months of age. **D)** By March 2015, 75% of NICU babies will receive a confirmatory diagnosis by two months post-discharge. **Status:** Preliminary data for NICU babies born in 2012 indicates that 67.74% of babies who were screened after 30 days of age received confirmation of hearing status. Of those children 40.9% received confirmation of hearing status by two months post screening (at the present time we do not capture the date of discharge). **E)** By March 2015, the percentage of children who are born in 2013 and who are lost to follow-up or documentation (LTF/D) between screening and confirmatory diagnosis will decrease to 10% or less. **Status:** Preliminary data for babies born in 2012 who did not pass newborn hearing screening indicates that 1.69% of the children were lost to follow-up and an additional 7.35% of babies' families were contacted but were unresponsive to follow-up recommendations. See the chart or table below for additional information about overall follow-up rates from 2009-2012.

	2009	2010	2011	2012
Passed/Normal Hearing	65.0%	69.6%	75.6%	73.8%
Diagnosed Hearing Loss	7.40%	6.2%	6.6%	6.1%
In Process	0%	0.3%	0.3%	4.2%
Other (Died, Moved, Refused)	4.3%	7.2%	7.6%	6.8%
LTF (Unable to Contact)	7.6%	3.9%	1.9%	1.7%
Parents Contacted but Unresponsive	15.8%	12.8%	8.0%	7.4%

Also, note the "Parents Contacted but Unresponsive" rate as compared to the rate of children who were truly "Lost-to-Follow-up."



Goal 3: The Indiana EHDI system will work collaboratively to ensure no less than 75% of children diagnosed with permanent hearing loss are enrolled in early intervention services before age 6 months. Objective A) Within 4 weeks of receiving confirmation of diagnosed hearing loss, the EHDI program will contact by letter, phone or video phone (reached or not reached) 95% of families with newly diagnosed children. **Status:** For children diagnosed in 2012, 81.2% of families were contacted within one month of the EHDI program receiving confirmation of the child's hearing loss. **B)** By March 2015, 90% of babies who develop hearing loss or who are found to have permanent hearing loss after six months of age will be enrolled in early intervention by three months post diagnosis. **Status:** Preliminary data indicates that 15 of 24 (62.5%) children who were born in 2012 and had delayed onset hearing loss were enrolled in early intervention. Of those children 3 were enrolled within 3 months post diagnosis, 1 was enrolled between 3-6 months after diagnosis, 2 was enrolled after six months of diagnosis and 9 additional children were enrolled but the age of enrollment is unknown. **C)** By March 2015, hearing technology status will be reported to the EHDI program on 90% of the children identified annually with hearing loss whose families are enrolled in GBYS**. Status:** Preliminary data for children born in 2012 who were diagnosed with hearing loss and enrolled in GBYS indicates that 63.38% of children were fit with hearing aids or cochlear implants. 12.67% of children had unilateral hearing loss and were not using amplification as recommended by their audiologist. The remaining 23.95% of children the status of hearing aid use is currently unknown or the children are still in the process of receiving their amplification.

Goal 4: The EHDI program will expand awareness and education about EHDI among primary care providers (PCP)/Medical Homes, Ear, Nose, & Throat (ENT) Specialists to enhance "1-3-6" as a Standard of Care and to ensure that appropriate medical care and intervention/education services are provided to children enrolled in their practice. Objective A) By March 2015, 95% of Primary Care Providers will be contacted by the EHDI program within one month of notification that a child did not pass newborn hearing screening. **Status:** For children born in 2012 the EHDI Program attempted to contact 100% of PCPs assigned to children not passing newborn hearing screening with 58.03% of PCPs being contacted within 30 days of the EHDI program being notified. For the first half of 2013, 61.42% of PCPs were contacted within one month of the EHDI program being notified. It is noted that some PCPs may not have been contacted within 30 days because 1) diagnostic reports supporting normal hearing or 2) the children remained in the NICU. **B)** By March 2015, 95% of Primary Care Providers will be contacted by the EHDI program when a child at risk for delayed onset of hearing loss is approximately 7 months of age and is in need of follow-up testing between 9 and 12 months of age. **Status:** 92.3% of PCPs for babies born in 2012 who were at risk for developing hearing loss received notification by mail that follow-up testing was recommended. **C)** By March 2015, Primary Care Provider Toolkits will be provided to the individual providers of 95% of children identified with permanent hearing loss. **Status:** Data for children diagnosed in 2012 indicates that 91.9% of PCPs were sent a tool kit, and 89.7% of PCPs were sent tool kits for children diagnosed in 2013. **D)** By June 2013, PCPs will be provided with a summary of the Joint Committee on Infant Hearing (JCIH) Early Intervention supplement (to be released in

2011) to improve awareness of intervention recommendations for children identified with hearing loss. **Status:** The JCIH Early Intervention supplement was published in mid 2013 but because of staffing constraints has not been sent out statewide. This will be accomplished during the next grant year by the EHDI Chapter Champion. **E)** By May 2012, in coordination with the IN AAP Chapter Champion, a 3- year plan to educate PCPs will be developed and implemented to improve awareness of newborn hearing screening follow-up recommendations, implications for delayed diagnosis of hearing loss, medical assessments, and interventions for children with diagnosed hearing loss. **Status: Met.** A 2012-2014 EHDI Chapter Champion Plan has been developed. **F)** By June 2013, an ENT EHDI Care Plan will be developed and disseminated to ENT physicians across Indiana. **Status:** The ENT EHDI Care Plan was reviewed and updates were made. Because of the implementation of the Center for Deaf and Hard of Hearing Education dissemination of the Care Plan has been postponed until contact information and branding for the new Center for Deaf and Hard of Hearing Education are in place and can be added to the Plan.

Goal 5: The EHDI program will expand awareness and education among parents about EHDI goals, resources, and formal family support programming through collaborative work with Maternal Infant Early Childhood Home Visiting programs (specifically, Healthy Families Indiana [HFI] and Nurse Family Partnerships [NFP], the Early Childhood Comprehensive System [a.k.a. Sunny Start] and Indiana Hands & Voices). Objective **A)** Beginning June 2012, EHDI will increase awareness of Early Hearing Detection & Intervention (EHDI) among Healthy Families Indiana (HFI) and Nurse-Family Partnerships (NFP) Home Visitors and families by providing at least two webinars annually about EHDI related topics. **Status:** A presentation was given in January 2013 to NFP Home Visitors by the EHDI Follow-up Coordinator and one of the EHDI Parent Consultants. Additional attempts to educate and collaborate with Healthy Families of Indiana and Nurse-Family Partnerships have been unsuccessful. EHDI will continue to reach out to these groups to provide information and support. **B)** Beginning June 2012, EHDI will increase awareness of Early Hearing Detection & Intervention (EHDI) among Sunny Start Core Partners (who represent public and private entities and parents of children with special healthcare needs by providing presentations at Sunny Start Core Partner meetings during Years 1 and 3. **Status:** An EHDI staff member continues to attend the Sunny Start Core Partners meetings on a quarterly basis. Updates about the EHDI program and the Center for Deaf and Hard of Hearing Education are shared with the group and included in the minutes of each meeting. **C)** Beginning June 2012, EHDI will increase awareness of Sunny Start resources among birthing facility personnel, audiologists, primary care providers, and early interventionists as they participate in the Early Hearing Detection and Intervention (EHDI) process by conducting at least two webinars annually. **Status:** Not started. Webinars will be offered in calendar year 2014. **D)** Beginning June 2012, EHDI will increase awareness of Sunny Start resources among families as they participate in the Early Hearing Detection and Intervention (EHDI) process by including materials in 100% of the EHDI Parent Toolkits provided. **Status:** Sunny Start materials were included in every parent tool kit sent by the EHDI Program. Unfortunately, because of budget constraints only the Indiana Ready Guide (Family Resource Guide) is being sent. The Ready Guide does include contact and website information for several Indiana State Department of Health Programs. Website information for Sunny Start Materials will be added to the Ready Guide when it is updated in 2014. **E)** By March 2015, Individualized Family Service Plan (IFSP) recommendations will be received by EHDI for 90%

of children whose families are enrolled in GBYS. **Status:** Release of information forms are presented to families enrolled in GBYS for the sharing of IFSP information with Indiana Hands & Voices and the EHDI program. The EHDI program faxes the signed release with an IFSP document request to the appropriate First Steps (Part C) System Point of Entry (SPOE) office. For children born in 2012 signed releases have been received for 62.5% of children enrolled in GBYS and early intervention services are known for 79.17% of children enrolled in GBYS. **F)** By March 2015, hearing technology status will be known for 90% of children whose families are enrolled in GBYS. **Status:** In Progress. Hearing aid and cochlear implant information is collected for individual children by the GBYS Parent Guide assigned to that family as it becomes available. See detailed data on this in Goal 3C **G)** By March 2015, child-centric information will be known related to the specific types of early intervention services provided for no less than 90% of children enrolled in GBYS. **Status:** In Progress. Early intervention direct services information (e.g. type of service) is collected for individual children either by the GBYS Parent Guides or by review of IFSP when a signed release is on file. As described in 5E above early intervention services are known for 79.17% of children enrolled in GBYS. **H)** By March 2015, early communication option(s) selections will be known for 90% of children diagnosed with hearing loss enrolled in GBYS so that families may be supported in their decisions and pursuit of appropriate services. **Status:** Communication opportunities/options are discussed with most families upon intake. Early communication choices were documented for 94.37% of families and indicated the following breakdown: American Sign Language (ASL): 1.41% Cued Speech/Language: 0% Listening and Spoken Language: 81.69 % and Total Communication 11.27%. The remaining 5.63% of families had not yet made a decision regarding communication options. It should be noted that this data reflects parents' choices during the early post-identification period. It should also be noted that data may be skewed based on deaf families often choosing to receive support services from the SKI*HI Parent Advisors. **I)** By April 2015, Indiana Hands & Voices will have planned, implemented and evaluated three annual EHDI Family Conferences for families of children diagnosed with hearing loss ages birth to six years. **Status:** Indiana Hands & Voices hosted the annual EHDI Family Conference on September 14, 2013 at Jameson Camp, a retreat camp setting in Indianapolis. Twenty-two families attended the conference which included a total of 47 parents and other adult family members and 49 children. Four families (total of 9 adults) whose language of the home is Spanish attended the conference. An additional 31 adult volunteers contributed in order to make the day successful. Highlights of the conference included keynote speaker, Karen Putz, an author, a parent and a hard of hearing adult. Karen shared the twists and turns of her journey and the wisdom she's learned along the way. Other presentations included the Expertise Among Us, Parent, Educator, and Professional, topical breakout sessions and a program on self-advocacy steps to success. The conference included 10 exhibitors and a Sibshop for siblings with typical hearing. **J)** By November 2012, the EHDI program will compensate family members, youth and consumers who are members of the EHDI Advisory Committee and are not paid to participate by another entity. **Status:** With the establishment of the Center for Deaf and Hard of Hearing Education (CDHHE) there have been no EHDI Advisory Committee meetings in the past 12 months. A new committee is being formed by the Director of the CDHHE and parent participants will be compensated for their participation on the committee.

Goal 6: Communicate with families through social (marketing) media tools to 1) encourage parents to "pay attention" to their baby's hearing and communication efforts and 2) to

locate resources and support if their child is diagnosed with hearing loss. Objective A) Beginning April 2012, the EHDI program will post EHDI-related information that is of interest to EHDI stakeholders on Face Book and Twitter once monthly. **Status:** This was done intermittently during this grant period. More regular postings will be attempted over the remainder of this grant cycle and beyond. **B)** By Sept 2012, a plan will be created with the Indiana Department of Education (DOE) to enable access to the Loss & Found DVD as an educational tool to high school students and educators and a method for increasing awareness about hearing and reducing lost to follow-up. **Status:** The EHDI Director reached out to the **C)** By September 2012, Indiana Hands & Voices will provide a monthly E-letter to all current GBYS families, past GBYS families, and the professionals that serve them to ensure that families and professionals are up to date on family support activities around the state. **Status:** Hands & Voices has been providing newsletters throughout this grant cycle at least monthly.

Goal 7: Enhance data quality, collection and management to improve tracking and surveillance through the EHDI Alert Response System (EARS). Objective A) By December 2013, the proportion of duplicate files will be reduced to less than 10% so that valid and verifiable data is provided from all reporting sources on children so that EARS and EHDI staff are able to identify, match, collect and report unduplicated and individually identifiable data on all Indiana occurrent births. **Status: Met**. **B)** On an ongoing basis, the EHDI program will work with the Genomics & Newborn Screening program to leverage Integrated Technology innovations and public health informatics solutions that serve EHDI stakeholders and particularly EARS users by participating in four meetings per year about public health informatics**. Status:** The Genomics & Newborn Screening program has contracted with OZ Systems to use their birth notification system and to develop electronic access "bridges" from pulse oximetry and hearing screening equipment to the ISDH Data Repository. Three hospitals began working with OZ in the spring of 2013. To date only one of the hospitals is able to send all three sets of data (newborn notification, hearing screening and pulse oximetry). The three remaining hospitals continue to attempt to implement this data transfer successfully. Work on this project will continue to determine its feasibility to be spread statewide. **C)** On an ongoing basis, 98% of Indiana birthing facilities will report babies to EHDI using the EARS system so that data quality and integrity will be enhanced. **Status:** Throughout 2013 all traditional hospitals in Indiana (N=101) submitted monthly reports through EARS with 83.95% of MSRs being submitted on time (by the 15th of the month for the previous month's children. 4 midwife facilities are reporting to EHDI with two of them completing the reports electronically and two reporting in paper format. **D)** By December 2013, 95% of DAE forms submitted by audiologists evaluating children will be electronically entered via the Diagnostic Audiology Evaluation (DAE) section of EARS web-based data system. **Status:** The proportion of DAE forms entered directly into EARS by audiologists continues to increase. In 2012, 91.5% of DAEs were submitted/entered directly into the data system and in 2013 93.1% were submitted/entered directly by audiologists. The remaining DAEs were entered by EHDI staff when received by mail or fax. The EHDI Follow-up Coordinator and the EHDI Regional Audiology Consultants continue to identify and train audiologists who are not currently using EARS.

Goal 8: Contribute to infrastructure development through core public health assessment, policy development and assurance functions. Objective **A)** On an annual basis (May 2012, 2013, 2014) inform and educate the public and families about the EHDI program, its statistic,

and progress, and "hot issues" through a "State of EHDI" document. Status: Because of the establishment of the Center for Deaf and Hard of Hearing Education and the ensuing staff changes the “State of EHDI” annual report has been delayed. It is anticipated that this document will not be available until 2015. **B)** On an ongoing basis, EHDI will participate in at least one quarterly Maternal & Child Health and non-Maternal & Child Health community collaborations and partnerships to identify and solve EHDI problems. Status: EHDI staff attended the Sunny Start Initiative meeting and/or the First Steps Interagency Coordinating Council (ICC) quarterly. **C)** By June 2012, plans will be developed and implemented to improve the capacity and competency of the public health and personal health workforce, as well as, the Part C early intervention and Part B education workforces to effectively and efficiently address the needs of children with hearing loss by providing technical support, trainings and dissemination of materials to Indiana professionals. **Status:** This objective is a key component of the Center for Deaf and Hard of Hearing Education and the Transition Plan that was developed to guide the Center. EHDI staff is actively working with the Center to improve services for children with hearing loss across the state. Additionally, EHDI staff has conducted a training through First Steps’ Part C training mechanism during this reporting period. A second training through First Steps is planned for March 7, 2014 and will focus on assessment services offered by the Center for Deaf and Hard of Hearing Education. **D)** By July 2012, EHDI and the State Head Start Collaboration Office will evaluate data obtained the Early Childhood Hearing Outreach (ECHO) and determine the feasibility of statewide spread through Indiana Early Head Start Programs. **Status:** Met and ongoing**.** In Sept of 2013, 2 of the Regional Consultants attended an ECHO workshop in Utah. The Regional Consultants have identified a few Early Head Start programs to train and one that needs a refresher course. Indiana is striving to spread the ECHO initiative across the state but it is taking time to accomplish this. **E)** By September 2012, EHDI will improve access to integrated community systems of care for children and their families across the EHDI process by identifying and implementing at least two quality improvement measures. **Status:** With the establishment of the Center for Deaf and Hard of Hearing Education two quality improvement projects are under development and should begin in the first quarterly of 2014. EHDI will be modifying procedures when children are diagnosed with hearing loss to include a referral to the centralized network (Center for Deaf and Hard of Hearing Education Network). Implementation of a centralized network of providers who work with deaf and hard of hearing children is being established. Child diagnosed with permanent hearing loss will be referred to this network (unless parents opt out) and providers with appropriate skills will be matched to families to assist in meeting IFSP goals. **F)** By March 2014, a plan will be developed to promote sustainability of the program aspects for which funding is being requested in this grant opportunity through the Maternal & Child Health Bureau. **Status:** Budget discussions related to Genomics and Newborn Screening as well as the Center for Deaf and Hard of Hearing Education are ongoing and are attempting to establish state funds to support work funded through this grant.

Goal 9: Conduct program evaluation activities to ensure that the Indiana EHDI program is achieving "1-3-6" and its other goals and objectives that lead to success for children with hearing loss. Objective A) By September 2012, ISDH EHDI program will collaborate with reporting sources by providing EARS training, feedback and performance metrics on at least an annual basis. **Status:** In 2013, the EHDI Regional Audiology Consultants (RC) provided targeted training to 77 hospitals, either in person, by phone or email. Of the 49 hospitals with

refer Rates outside of 1.5-4%, 41 had template training by an RC. In addition, another 196 hospital contacts were completed by the RCs. The end of the year report highlighted hospital concerns with follow-up by area audiologists. B) By September 2012, a formal program evaluation plan will be developed that includes at least one hospital survey, one audiologist survey, and one survey for parents. Status: Met. C) Quarterly, EHDI will run data reports on all "Measures of Success" to monitor progress on program goals and objectives. Status: Ongoing. The EHDI program continuously runs reports to monitor overall screening and follow-up rates. In addition, families and physicians assigned to children who did not pass the hearing screening and are almost one year of age are contacted one last time to encourage follow-up, to answer questions, and to obtain follow-up results.

Significant Changes:

The opening of the Center for Deaf and Hard of Hearing Education. The establishment of the Center will enable continued development of a statewide, comprehensive, coordinated system to support children who have hearing loss and their families. It is anticipated that implementation of the CDHHE and ensuing program development will improve EHDI's main goals of diagnosis before three months of age and enrollment in early intervention by six months of age. In addition, development of expanded data items to track the progress of individual children after diagnosis is underway and will be piloted in 2014.

In addition, the Guide By Your Side Parent Program Coordinator, Lisa Kovacs resigned from her position in December 2013. She accepted a position with Hands & Voices Head Quaters as their Director of Programs. Lisa Condes, who has been functioning as both an EHDI Parent Consultant and a GBYS Outreach Coordinator for the last couple of years, will be moving into the GBYS Parent Program Coordinator role. Lisa Kovacs will continue on with the program through at least the end of this grant cycle to ensure a smooth transition. With Ms. Condes moving into her new role Julie Swaim one of our other EHDI Parent Consultants will be adding to her job duties and will be assisting with some of the GBYS calls to newly diagnosed families. A new EHDI Parent Consultant, Toni Harpster, was hired and will begin working January 13, 2014.

Plans for Upcoming Budget Year: Plans for the upcoming budget year are embedded in the Goals and Objectives section of this report. There are no major modifications to the plans indicated in the initial grant application at this time. If awarded for the upcoming budget year, HRSA monies would be used primarily to fund the EHDI Parent Consultants who conduct follow-up activities for babies who do not pass newborn hearing screening and the Guide By Your Side program for families of children identified with hearing loss. The Parent Consultants and Guide By Your Side program play central roles in ensuring that individual families are connected to necessary services and understand their role, and that of professionals, in helping their child realize the benefits of early identification of hearing loss.

Estimated Unobligated Balance: It is anticipated that approximately $120,000 will remain unencumbered. These funds were not spent because of significant illnesses experienced by the EHDI Parent Consultants and the Guide By Your Side (GBYS) Outreach Coordinator. In addition, a reduction in the number of hours worked by the GBYS Parent Guides was experienced during this grant cycle. The unobligated expenses will be formally requested as carryover to assist in funding a portion of the EHDI Follow-up Coordinator's salary and for

purchasing equipment for the regional centers for the Center of Deaf and Hard of Hearing Education that are slated to open in the third quarter of 2014.

The EHDI program is grateful for the support of HRSA in this endeavor and appreciates being considered for funding in the new budget year.

Goal 1
The Indiana EHDI system will work collaboratively to ensure that 97% of babies receive newborn hearing screening before age one month.
Objectives
A) By Jan 2014, screening results will be received by the EHDI program on all children screened at all birthing facilities

C) By Oct 2012, capacity for screening by midwife personnel will increase by adding loaner screening equipment to at least three midwifery practices that are currently not screening newborns
D) By Sept 2012, design updated hospital training and provide at least 4 webinars annually.
E) By March 2016, 98% of birthing facilities will use EHDI-designed materials with parents that emphasize the importance of UNHS and follow-up.
Goal 2

The Indiana EHDI system will work collaboratively to ensure that no less than 75% of children of babies who fail to pass newborn hearing screening receive confirmatory diagnosis of hearing status before age 3 months
Objectives
A) Annually, the EHDI program will attempt to contact 100% of families of babies who do not pass newborn hearing screening and are reported to the EHDI program and who have not yet received diagnostic follow-up will be contacted by the EHDI program within one month of notification in the EHDI EARS system
B) By March 2015, when diagnostic results are not received for children who do not pass newborn hearing screening by the EHDI program within 75 days of initial EHDI program contact, the EHDI program will attempt to re-contact no less than 100% of the remaining families will be contacted by phone and letter
C) By March 2015, 75% of Indiana non-NICU babies not passing UNHS will receive a confirmatory diagnosis by 3 months of age.

D) By March 2015, 75% of NICU babies will receive a confirmatory diagnosis by two months post-discharge.
E) By March 2015, the percentage of children who are born in 2013 and who are lost to follow-up or documentation between screening and confirmatory diagnosis will decrease to 10% or less
Goal 3
The Indiana EHDI system will work collaboratively to ensure no less than 75% of children diagnosed with permanent hearing loss are enrolled in early intervention services before age 6 months
Objectives

A) Within 4 weeks of receiving confirmation of diagnosed hearing loss, the EHDI program will contact by letter, phone or video phone (reached or not reached) 95% of families with newly diagnosed children
B) By March 2015, 90% of babies who develop hearing loss or who are found to have permanent hearing loss after six months of age will be enrolled in early intervention by three months post diagnosis.

C) By March 2015, hearing technology status will be reported to the EHDI program on 95% of the children identified annually with hearing loss whose families are enrolled in GBYS.
Goal 4
The EHDI program will expand awareness and education about EHDI among primary care providers (PCP)/Medical Homes, Ear, Nose, & Throat (ENT) Specialists to enhance "1-3-6" as a Standard of Care and to ensure that appropriate medical care and intervention/education services are provided to children enrolled in their practice
Objectives
A) By March 2015, 95% of Primary Care Providers will be contacted by the EHDI program within one month of notification that a child did not pass newborn hearing screening
B) By March 2015, 95% of Primary Care Providers will be contacted by the EHDI program when a child at risk for delayed onset of hearing loss is approximately 7 months of age and is in need of follow-up testing between 9 and 12 months of age.

C) By March 2015, Primary Care Provider Toolkits will be provided to the individual providers of 95% of children identified with permanent hearing loss.
D) By June 2013, PCPs will be provided with a summary of the Joint Committee on Infant Hearing (JCIH) Early Intervention supplement (to be released in 2011) to improve awareness of intervention recommendations for children identified with hearing loss.
D) By May 2012, in coordination with the IN AAP Chapter Champion, a 3- year plan to educate PCPs will be developed and implemented to improve awareness of newborn hearing screening follow-up recommendations, implications for delayed diagnosis of hearing loss, medical assessments, and interventions for children with diagnosed hearing loss.
E) By June 2013, a ENT EHDI Care Plan will be developed and disseminated to ENT physicians across Indiana
Goal 5

The EHDI program will expand awareness and education among parents about EHDI goals, resources, and formal family support programming through collaborative work with Maternal Infant Early Childhood Home Visiting programs (specifically, Healthy Families Indiana [HFI] and Nurse Family Partnerships [NFP]), the Early Childhood Comprehensive System (a.k.a. Sunny Start) and Indiana Hands & Voices
Objectives
A) Beginning June 2012, EHDI will increase awareness of Early Hearing Detection & Intervention (EHDI) among Healthy Families Indiana (HFI) and Nurse-Family Partnerships (NFP) Home Visitors and families by providing at least two webinars annually about EHDI related topics
B) Beginning June 2012, EHDI will increase awareness of Early Hearing Detection & Intervention (EHDI) among Sunny Start Core Partners (who represent public and private entities and parents of children with special healthcare needs by providing presentations at Sunny Start Core Partner meetings during Years 1 and 3.

C) Beginning June 2012, EHDI will increase awareness of Sunny Start resources among birthing facility personnel, audiologists, primary care providers, and early interventionists as they participate in the Early Hearing Detection and Intervention (EHDI) process by conducting at least two webinars annually
D) Beginning June 2012, EHDI will increase awareness of Sunny Start resources among families as they participate in the Early Hearing Detection and Intervention (EHDI) process by including materials in 100% of the EHDI Parent Toolkits provided
E) By March 2015, Individualized Family Service Plan (IFSP) recommendations will be received by EHDI for 90% of children whose families are enrolled in GBYS
F) By March 2015, hearing technology status will be known for 90% of children whose families are enrolled in GBYS

G) By March 2015, child-centric information will be known related to the specific types of early intervention services provided for no less than 90% of children enrolled in GBYS
H) By March 2015, early communication option(s) selections will be known for 90% of children diagnosed with hearing loss enrolled in GBYS so that families may be supported in their decisions and pursuit of appropriate services
I) By April 2015, Indiana Hands & Voices will have planned, implemented and evaluated three annual EHDI Family Conferences for families of children diagnosed with hearing loss ages birth to six years
J) By November 2012, the EHDI program will compensate family members, youth and consumers who are members of the EHDI Advisory Committee and are not paid to participate by another entity

Goal 6
Communicate with families through social (marketing) media tools to 1) encourage parents to "pay attention" to their baby's hearing and communication efforts and 2) to locate resources and support if their child is diagnosed with hearing loss
Objectives
A) Beginning April 2012, the EHDI program will post EHDI-related information that is of interest to EHDI stakeholders on Face Book and Twitter once monthly.
B) By Sept 2012, a plan will be created with the Indiana Department of Education to enable access to the Loss & Found DVD as an educational tool to high school students and educators and a method for increasing awarenss about hearing and reducing lost to follow-up
C) By September 2012, Indiana Hands & Voices will provide a monthly E-letter to all current GBYS families, past GBYS families, and the professionals that serve them to ensure that families and professionals are up to date on family support activities around the state.
Goal 7
Enhance data quality, collection and management to improve tracking and surveillance through the EHDI Alert Response System (EARS)

Objectives
A) By December 2013, the proportion of duplicate files will be reduced to less than 10% so that valid and verifiable data is provided from all reporting sources on children so that EARS and EHDI staff are able to identify, match, collect and report unduplicated and individually identifiable data on all Indiana occurrent births
B) On an ongoing basis, the EHDI program will work the Genomics & Newborn Screening program to leverage Integrated Technology innovations and public health informatics solutions that serve EHDI stakeholders and particularly EARS users by participating in four meetings per year about public health informatics
C) On an ongoing basis, 98% of Indiana birthing facilities will report babies to EHDI using the EARS system so that data quality and integrity will be enhanced

D) By December 2013, 95% of DAE forms submitted by audiologists evaluating children will be electronically via the Diagnostic Audiology Evaluation (DAE) section of EARS web-based data system
Goal 8
Contribute to infrastructure development through core public health assessment, policy development and assurance functions
Objectives
A) On an annual basis (May 2012, 2013, 2014) inform and educate the public and families about the EHDI program, its statistic, and progress, and "hot issues" through a "State of EHDI" document
B) On an ongoing basis, EHDI will participate in at least one quarterly Maternal & Child Health and non-Maternal & Child Health community collaborations and partnerships to identify and solve EHDI problems.

C) By June 2012, plans will be developed and implemented to improve the capacity and competency of the public health and personal health workforce, as well as, the Part C early intervention and Part B education workforces to effectively and efficiently address the needs of children with hearing loss by providing technical support, trainings and dissemination of materials to Indiana professionals.
D) By July 2012, EHDI and the State Head Start Collaboration Office will evaluate data obtained the Early Childhood Hearnig Outreach (ECHO) and determine the feasibilty of statewide spread through Indiana Early Head Start Programs.

E) By September 2012, EHDI will improve access to integrated community systems of care for children and their families across the EHDI process by identifying and implementing at least two quality improvement measures.
F) By March 2014, a plan will be developed to promote sustainability of the program aspects for which funding is being requested in this grant opportunity through the Maternal & Child Health Bureau.
Goal 9
Conduct program evaluation activities to ensure that the Indiana EHDI program is achieving "1-3-6" and its other goals and objectives that lead to success for children with hearing loss
Objectives

A) By September 2012, ISDH EHDI will collaborate with reporting sources by providing EARS training, feedback and performance metrics on at least an annual basis.
B) By September 2012, a formal program evaluation plan will be developed that includes at least one hospital survey, one audiologist survey, and one survey for parents

C) Quarterly, EHDI will run data reports on all "Measures of Success" to monitor progress on program goals and objectives

Measures of Success
● 97% of babies born in 2013 will receive newborn hearing screening before age one month. ● 90% of the children born in 2014 will have documented UNHS results available to EHDI staff ● By June 2013, one hospital will be transmitting UNHS results electronically to ISDH on all children ● By September 2013, EARS will create automatic alerts based on electronic UNHS results received from pilot hospitals ● By Jan 2014, 90% of hospitals will be transmitting UNHS results electronically to ISDH on all children
Activities/Steps
1) Work with vendor to develop plan for implementation 2) Work with screening facilities to ensure capacity for sharing screening results directly from hearing screening equipment 3) Pilot direct sharing of screening info in one hospital system 4) Add one additional hospital system in each of Indiana's regions 5) Ongoing study of results and process modifications as needed 6) Spread statewide **Program Staff Responsible**: IT Staff, EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist

1) Put out competitive application for loaner screening equipment use 2) Review applications and select recipients 3) Complete contract process with each facility 4) Ship or bring equipment to facility **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants
1) Update existing or create new presentation 2) Place on website (www.hearing.IN.gov) 3) Invite personnel to participate in one of four live webinars annually **Program Staff Responsible**: EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants
1) Continue to provide EHDI brochures (General FAQs and Referral brochure {if baby needs aud eval] in English and Spanish to ensure that screening and any recommended follow-up occurs) to all birthing hospitals, birthing facilities and known midwives 2) Increase the number of birthing facility prenatal classes that are using the Loss and Found DVD 3) Increase the number of hospitals that are using the Loss and Found DVD (currenlty 30/98 use) **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants
Measures of Success

Activities/Steps
1) Contact is attempted with families and primary care physicians (PCP) by phone and letter per EHDI protocols **Program Staff Responsible:** EHDI Parent Consultants
1) Contact is attempted with family and PCPs by phone and letter per EHDI protocols 2) Contact is attempted with audiologist with whom diagnostic testing was scheduled if provided by hospital **Program Staff Responsible:** EHDI Parent Consultants, EHDI Follow-up Coordinator, EHDI Program Specialist
1) Recommendations will be provided to physician community in one annual presentation 2) EARS data management system will be used to track children 3) Communication with parents, physicians, audiologists per EHDI protocols will be followed to ensure follow-up **Program Staff Responsible:** AAP EHDI Chapter Champion, EHDI Directors, EHDI Parent Consultants, EHDI Follow-up Coordinator, EHDI Program Specialist

1) Recommendations will be provided to physician community in one annual presentation 2) EARS data management system will be used to track children 3) Communication with parents, physicians, audiologists per EHDI protocols will be followed to ensure follow-up **Program Staff Responsible:** AAP EHDI Chapter Champion, EHDI Directors, EHDI Parent Consultants, EHDI Follow-up Coordinator, EHDI Program Specialist
1) By March 2013 at least 2 lost to follow-up characteristics will be identified and 2 new activities to improve access to services will be implemented. **Program Staff Responsible:** EHDI Program Director, EHDI Follow-up Cooridinator, EHDI Program Specialist, GBYS Program Coordinator, GBYS Family Outreach Coordinator
Measures of Success
● 95% of families will receive a toolkit within 4 weeks of diagnosis notification ● 95% of families will be contacted by phone within 4 weeks of diagnosis notification ● 100% of families opting into GBYS will be contacted by a Parent Guide within 3 days of enrollment date
Activities/Steps

1) Families will receive info in EHDI Parent Toolkit 2) Family contact will be attempted by phone within four weeks of confirmation of loss 3) GBYS follow-up letter will be sent if not able to connect with family via phone 4) If reached, services will be discussed and family will be offered GBYS 5) GBYS assists family in connecting with Early Intervention if this has not yet occurred **Program Staff Responsible:** EHDI Follow-up Cooridinator, EHDI Program Specialist, GBYS Program Coordinator
1) Families will receive info in EHDI Parent Toolkit which will continue to include materials about Maternal & Children Health, Part C Early Intervention, Children with Special Health Care Needs, family support organziations, and other health and social support services 2) Family contact will be attempted by phone within four weeks of confirmation of loss 3) GBYS follow-up letter will be sent if not able to connect with family via phone 4) If reached, services will be discussed and family will be offered GBYS 5) GBYS assists family in connecting with Early Intervention if this has not yet occurred **Program Staff Responsible:** EHDI Follow-up Cooridinator, EHDI Program Specialist, GBYS Program Coordinator

1) Families will be queried about current status and any plans related to amplification [in a culturally-sensitive, family-focused manner] 2) Results will note status in EARS Outcomes Form **Program Staff Responsible:** GBYS Program Coordinator, GBYS Parent Guides
Measures of Success
● 95% of letters sent to PCP about children not passing UNHS will be sent within one month of notification to EHDI program ● 95% of letters sent to PCP about children diagnosed with hearing loss will be sent within one month of notification to EHDI program ● By May 2012, 3-year PCP plan will be completed ● ENT Care plan will be distributed to at least 20 ENT practices
Activities/Steps
1) Per current practice, the EHDI program will mail a copy of the parent F/U letter sent to the PCP and include a fax-back/mail-back form that can be used to share results with EHDI **Program Staff Responsible:** EHDI Parent Consulant
1) Per current practice, the EHDI program will mail a copy of the parent follow-up letter within one month of receiving the initial alert and then another letter at 7 months of age to both mother and PCP and include a fax-back/mail-back form that can be used to share results with EHDI **Program Staff Responsible:** EHDI program support staff

1) Letters of notification and toolkit materials will be mailed to child's PCP upon confirmed diagnosis of hearing loss **Program Staff Responsible:** EHDI Follow-up Coordinator, GBYS Parent Program Coordinator
1) Will be shared this info as part of presentations conducted for physicians at least once annually (upon availability of the document) 2) An electronic version will be placed at www.hearing.IN.gov and emailed to our list of physicians **Program Staff Responsible:** EHDI Director, AAP EHDI Chapter Champion, IT Staff
1) 3 year plan for education of PCPs across the state will be developed 2) Educational materials and methods of integrating the medical home into follow-up care will be developed 3) A fact sheet for ENTs will be developed **Program Staff Responsible:** EHDI Director, AAP EHDI Chapter Champion
1) An ENT Care Plan was developed by our NICHQ team and will be assessed for any changes that might be needed 2) The ENT Care Plan will be disseminated via email and placed at www.hearing.IN.gov **Program Staff Responsible:** EHDI Director, AAP EHDI Chapter Champion, EHDI Follow-up Coordinator, EHDI Program Specialist, EHDI Regional Audiology Consultants, EHDI Advisory Committee, NICHQ team
Measures of Success

● At least two webinars are held annually by EHDI for HFI, NFP, and Sunny Start ● At least two webinars are held annually for birthing facility personnel, audiologists, primary care providers, and early interventionists to share HFI, NFP and Sunny Start information ● By April 2015, 90% of children enrolled in GBYS will have IFSP, hearing technology, communication, and early intervention services documented in EARS ● By November 2012, two new EHDI Advisory Committee members will added that represent oneparent, one Deaf or Hard of Hearing college student or young adult
Activities/Steps
1) EHDI will design a training for HFI and NFP Home Visitors 2) Trainings will be conducted and resources provided for staff on newborn hearing screening, signs of hearing loss, impact of hearing loss, communication development and appropriate referral mechanisms, IN Hands & Voices, GBYS, and the Statewide Referral Network for Deaf and Hard of Hearing Children 3) A set of questions will be developed and introduced that HFI and NFP Home Visitors can use with families to reduce loss to follow-up **Program Staff Responsible:** EHDI Program Director, EHDI Follow-up Coordinator
1) Continue EHDI participation as a Sunny Start Core Partner 2) Conduct presentations at Sunny Start Core Partners meetings in Year 1 and 3 of the grant **Program Staff Responsible:** EHDI Program Director

1) Provide the Early Childhood Meeting Place link for easy access to resources such as the Family Resource Fact Sheets and the Wellness Passport for Indiana's Kids to a) Indiana birthing facilities and b) audiologists, primary care providers, and early interventionists to share with families at appointments or home visits **Program Staff Responsible:** EHDI Program Director, EHDI Follow-up Coordinator, EHDI Program Specialist, GBYS Coordinator and Parent Guides
1) Provide selected Sunny Start resources (i.e. financial) to families of newly diagnosed children in the EHDI Parent Toolkit to enhance likehood of appropriate follow-up **Program Staff Responsible:** EHDI Follow-up Coordinator, EHDI Program Specialist and EHDI Parent Consultant, GBYS Program Coordinator and Parent Guides
1) Families will be asked to sign a Universal Release form that will allow for sharing of IFSP info with EHDI 2) Release will be scanned and uploaded into EARS **Program Staff Responsible:** GBYS Program Coordinator and Parent Guides
1) Families will be asked for information related to their child's hearing technology status 2) Info will be reported in EARS **Program Staff Responsible:** GBYS Program Coordinator and Parent Guides

1) IFSP or GBYS Parent Guide data will be viewed to determine services child is providing and documented on EARS Outcomes Form **Program Staff Responsible:** EHDI Follow-up Coordinator, GBYS Program Coordinator, and GBYS Parent Guides
1) In a culturally-sensitive, family-centered manner, families will be queried during post-diagnosis phone call and during GBYS parent-to-parent support contacts about any decisions they have made related to communication mode or methodology 2) This data will be documented on EARS Outcomes Form **Program Staff Responsible:** GBYS Program Coordinator and Parent Guides
1) Convene annual planning committee and subcommittees 2) Plan culturally-sensitive family-centered conference 3) Promote, Conduct and Evaluate and 4) Report results to EHDI **Program Staff Responsible:** GBYS Program Coordinator, H&V Family Outreach Coordinator, and H & V Executive Director
1) Bring a recommendation of adding two new members (one parent, one Deaf or Hard of Hearing college student or young adult) to the EHDI Advisory Committee 2) If approved, identify candidates 3) Invite to participate and compensate for participation **Program Staff Responsible:** EHDI Director, H & V Executive Director

Measures of Success
● By April 2012, monthly Facebook posts, tweets, and e-newsletters will be completed ● By Sept 2012, a plan for sharing Lost & Found video with Indiana high schools will be developed and implemented
Activities/Steps
1) Face Book posts will be developed 2) Information will be posted on the Indiana Hands & Voices (IN H&V) Face Book and tweet will be sent via the IN H&V Twitter account. **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, GBYS Coordinator, IN H & V Excutive Director
1) Meet with the IN Dept of Ed Health Services Director 2) Identify possible venues 3) Plan and implement plan **Program Staff Responsible:** EHDI Director, GBYS Coordinator, IN H&V Excutive Director
1) Design newsletter 2) Send for review to IN H&V Executivie Director and GBYS Coordindator 3) Send out quarterly beginning Sept 2012 **Program Staff Responsible:** EHDI Director, GBYS Coordinator, IN H&V Excutive Director
Measures of Success
● By December 2013, duplicate records will be less than 10% of records in EARS ● Ongoing, 98% of hospitals will use EARS ● By December 2013, 95% of DAE forms will be submitted electronically

Activities/Steps
1) Develop program protocols for account monitoring and organization management 2) Fully implement current Data Audit Tool with all facilities to identify duplicate records 3) Develop Data Management Tool for dealing with duplicate records easily and quickly 4) Merging of duplicate records **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EARS Program Specialist, IT staff, and UNHS Nurse Coordinator
1) Continue to participate in meetings of stakeholders and Health Information Exchange Organizations 2) Apply knowledge gained, as appropriate, to integrated data system plans **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator
1) Provide technical assistance as needed to birthing facilities 2) Provide one-on-one training to new facility staff who report in EARS 3) Offer webinar trainings four times annually 4) Conduct face-to-face visits annually with 5 to 10% of birthing facilities (visits reserved for those most in need) **Program Staff Responsible:** EHDI Follow-up Coordinator, EARS Specialist, Regional Audiology Consultants

1) Provide annual EARS trainings
2) Quarterly, send EHDI-grams to audiologists to provide training, announcement and program updates

Program Staff Responsible: EHDI Follow-up Coordinator, EARS Specialists, Regional Audiology Consultants

Measures of Success

● State of EHDI report is developed by May 2012
● At least two opportunities for improvement within the larger EHDI systerm are identified and plans developed to address the issues

Activities/Steps

1) November 2011create document plan including content
2) February 2012, data will be pulled
3) March 2012 first draft to be completed
4) April 2012 final document reivew
5) May 2012 document to be sent out via email and post to www.hearing.IN.gov

Program Staff Responsible: EHDI Director, EHDI Follow-up Coordinator, EARS Specialist

1) Participate in quarterly Sunny Start meetings 2) Participate in monthly Life Course planning meetings
3) At least two State Part C meetings annually

Program Staff Responsible: EHDI Director

1) Develop a two-year plan with Dr. Karen Goehl (who has offered to share funding for activities) for professional development of the EHDI, Part C and Part B workforce that provides services or wishes to provide services to children with hearing loss 2) Develop a plan to target a minimum of six audiology practices in need of support and education to either develop or improve follow-up evaluation capacity and streamline recommendations to be consistent with "Indiana's Best Practices in Audiology" document **Program Staff Responsible:** EHDI Director, Regional Audiology Consultants, GBYS Program Coordinator, EHDI Follow-up Coordinator
1) By July 2012, the EHDI program will conclude its involvement in the Early Childhood Hearing Outreach (ECHO) pilot project that is currently underway with three Indiana Early Head Start programs 2) By June 2012, the EHDI program will evaluate the feasibility and make recommendations related to statewide spread of the Early Childhood Hearing Outreach (ECHO) with Indiana Early Head Start Programs. **Program Staff Responsible:** EHDI Director

1) By Sept 2012, develop a Universal Release of Information form to enhance sharing of information among agencies that participate in the EHDI process 2) By Sept 2012, at least two quality improvement projects will identified and a plan to address them created and implemented 3) Provision of two First Steps forums to ensure that audiologists and early intervention personnel understand and communicate to families the purpose and flow of EHDI. **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, Regional Audiology Consultants
1) With Indiana Hands & Voices, by March 2014, develop a written sustainability plan **Program Staff Responsibilty:** EHDI Director, Indiana Hands & Voices Executive Director, GBYS Coordinator
Measures of Success
● By September 2012, template will be available to assist with identifying areas of concern with hospitals UNHS programs ● By January 2013 survey results will be available ● By February 2013 at least two quality improvement activities will be planned, studies and implemented
Activities/Steps

1) A performance improvement template will be developed for use with birthing facilities with issues related to screening rates, referral rates, and scheduling of follow-up appointments prior to hospital discharge for infants not passing UNHS **Program Staff Responsible:** EHDI Director, Regional Audiology Consultants, EHDI follow-up Coordinator, EARS Program Specialist
1) EHDI Advisory Committee will receive draft of evaluation plan and provided an opportunity to provide input 2) Develop a plan and timeline to conduct a comprehensive evaluation 3) Surveys will be created and sent out based on the developed plan 4) Surveys will be returned and data analyzed 5) EHDI Staff will discuss results, next steps, and quality improvement modifications that are needed **Program Staff Responsible:** EHDI Director, EHDI Follow-up Coordinator, EARS Program Specialist, Regional Consultants, GBYS Program Coordinator, Indiana Hands & Voices Executive

1) Analysis of "Measures of Success" will be used to conduct quantititive assessement of data items and to answer normative and causitive questions (as discussed in Program Evaluation section) 2) Data will be shared with program staff and stakeholders at EHDI Advisory Committee meetings 3) Data will be evaluated to inform EHDI of need for course corrections and new directions 4) Data will be reported in grant progress reports 5) Statistics will be made available to the public in presentations on the website **Program Staff Responsible:** EHDI Program Director, EHDI Follow-up Coordinator, IT Staff, Epidemiologist

The EHDI Program will promote the importance of diagnostic testing after not passing newborn hearing screening among families and professionals to ensure that 75% of children in need of follow-up receive confirmation of hearing status before three months of age

- Within 3 months of diagnosis, __% of families with newly diagnosed children born in 2013 will be enrolled in GBYS –**Lisa nor I are sure this should be an objectivel? Thoughts about having an objective for number/% enrolled in GBYS?**

Within 3 months of diagnosis, ___% of children born in 2013 and enrolled in GBYS will be fitted with amplification (when appropriate) –**Should we include this objective?**