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Name of Grantee: Indiana State Department of Health
Address of Grantee: 2 N. Meridian, Indianapolis, IN 46204
Principal Investigator: Gayla Hutsell Guignard
Business Official: Rebecca Chauhan
EHDI Coordinator: Julie Schulte, MA, CCC-A (Interim EHDI Coordinator)
Name/Title of person completing this report: Julie Schulte
Email Address: juschulte@isdh.in.gov
Phone Number: Phone: (317) 233-1264

A. Executive Summary:

Since its inception in 2000, the Indiana Early Hearing Detection and Intervention (EHDI) program has been administered through the Genomics and Newborn Hearing Screening program at the Indiana State Department of Health (ISDH). As described in previous reports, Indiana law was amended in 2012 to establish a Center for Deaf and Hard of Hearing Education (CDHHE) (IC 20-35-11) that will follow children with hearing loss from birth to 21 years of age. With this legislative change the EHDI program beginning July 1, 2013 will be reorganized from its current location under the Genomics and Newborn Screening Program within the Maternal and Children's Health Division of ISDH to the newly formed CDHHE which will also be located under ISDH.

The primary purpose of the CDHHE will be to follow children who have been diagnosed with permanent hearing loss from birth to 21 years of age. As part of the CDHHE, the EHDI program will continue to be to ensure that children born throughout Indiana will receive quality services including universal newborn hearing screening, early detection of hearing loss, and enrollment in early intervention. The current web-based data system called the EHDI Alert Response System (EARS) will continue to be used and will likely be modified to enable tracking of children with hearing loss from birth to school exit.

During this reporting period (July 1, 2012 to June 30, 2013), the EHDI program has continued to strive to meet the 1-3-6 goals of screening all babies by one month of age, confirming hearing status of children before three months of age, and enrolling children with diagnosed hearing loss in early intervention by six months of age. In addition, emphasis on methods to improve data quality and quantity will continue. The additional mandate to follow children through school exit presents many new opportunities for programmatic growth as well as growth of our EHDI Information System (IS).

Staff and Organization Updates

During this reporting period several staff changes occurred that impacted the work of the EHDI program. Shortly after Governor Mitch Daniels signed House Enrolled Act 1367 into law establishing the Center for Deaf and Hard of Hearing Education (CDHHE), Gayla Hutsell Guignard, EHDI Program Director, was invited to work with Indiana's Office of Management and Budget (OMB) as the internal content expert for design of the Center. Ms. Hutsell worked at OMB from March to October 2012. During this time the EHDI Follow-up Coordinator, Julie

Schulte, served as the Interim EHDI Program Director. In May 2013, Ms. Hutsell was hired as the CDHHE Director and began her new role on June 3, 2013. Ms. Schulte has become the Interim EHDI Program Director and will continue in that role until a full-time EHDI Program Director can be hired.

In anticipation of EHDI moving programmatically from Genomics and Newborn Screening to the Center for Deaf and Hard of Hearing Education (CDHHE), job responsibilities have been shifted to enable the newborn hearing screening portion of the program to remain within the Genomics and Newborn Screening program. Holly Heindselman, Newborn Screening Follow-up Coordinator, has become the primary contact for Indiana's 100+ hospitals for all newborn screenings including universal newborn hearing screening, heel stick and pulse oximetry used to screen for congenital heart disease. Once a hearing screening has occurred, ongoing follow-up will be conducted by the EHDI staff in the same manner as it has been done for several years.

The EHDI Regional Audiology Consultants (RCs) have been an integral part of the EHDI program for many years. The RCs have assisted EHDI in providing face-to-face technical support to hospitals across the state. Unfortunately, the RCs who covered the northwestern part of Indiana, Valari Koziel and Evelyn Sell, have resigned. A new RC for northwestern Indiana has been identified and will begin in October. Funds that remained unobligated at the end of this grant cycle were a result of RCs not using hours that had been allotted to them to use throughout the year. When funds were budgeted for year three, the allotment of hours was modified to ensure that the amount of unobligated funds will be as minimal as possible.

Bob Bowman the past director of the Genomics and Newborn Screening Program has become the Director of the Maternal and Children's Health Division. Mr. Bowman has begun the process of hiring a new Genomics and Newborn Screening program director and anticipates hiring that person by the end of 2013.

Policy/Legislative Changes:

During the 2012 legislative session House Enrolled Act 1135 (HEA 1135) was passed which enabled nurse midwives to be licensed within the state of Indiana and is included in Attachment B. The law went into effect July 1, 2013. HEA 1135 mandates that the "Practice of midwifery" includes several things including "normal newborn care". It also states that "the certified direct entry midwife must provide an initial screening of a client that includes an assessment of health conditions that require a referral to a physician..." With the passage of this law the Genomics and Newborn Screening program has experienced an increased number of contacts from midwives inquiring about state procedures for completion and reporting of newborn screens. Discussions will continue and assistance will be provided to ensure that midwives have the support needed to fulfill HEA 1135.

General and Program Information:

The daily work of the EHDI program continues to be facilitated through the web-based data system called EARS (EHDI Alert Response System). EARS is used as a means to document follow-up status and collect EHDI related data and integrate it with the larger Integrated Data Store (IDS). The IDS includes data from a variety of data sources including vital records (birth and death), newborn screening, cystic fibrosis, and others. EARS and IDS assist EHDI in

conducting ongoing monitoring and surveillance activities. The entire process within EARS typically begins with a hospital reporting a child who needs follow-up. The children reported by the hospitals did not receive UNHS, did not pass UNHS, or passed UNHS but are at risk for delayed onset hearing loss. The alerts created by the entry of these children notify appropriate staff members that attention to a particular child is needed. Once alerted, the NBS Follow-up Coordinator contacts the hospital, family and PCP by phone and perhaps letter as determined by EARS and EHDI Protocols. EARS alerts will continue to prompt the NBS Follow-up Coordinator that additional work is needed until the child is screened, a religious waiver is signed or the family outwardly refuses the screening and become an “unauthorized refusal”.

The EHDI Parent Consultants continue to provide the first follow-up activities when the program is notified of a child who did not pass. Annually, this represents about 2,500 children. The Parent Consultants attempt to contact all families of children who did not pass UNHS to ensure that children are scheduled for appropriate diagnostic follow-up. While the majority of children receive their follow-up in a timely manner, the remaining children receive considerable attention by the EHDI Parent Consultants. Numerous phone calls and letters are sent to the families and primary care providers (PCPs) in an attempt to express the importance of timely follow-up and to provide assistance. The EARS alerts prompt the Parent Consultants at predetermined intervals and follow-up continues until the hearing status of the child is confirmed, the family refuses to have the follow-up completed or the family is unresponsive to the attempts to assist them.

When a diagnostic audiology evaluation (DAE) form is entered into EARS, appropriate alerts are generated for the EHDI Follow-up Coordinator. If a DAE is submitted that supports normal hearing, a “Passed DAE” alert is generated and the file is closed automatically. If a DAE form is received that indicates additional testing is warranted then the next alert is delayed until the follow-up date specified by the clinical audiologist has passed. If an additional DAE form is not received by the time the follow-up appointment was to have occurred, the EHDI Follow-up Coordinator is alerted to continue the follow-up by contacting audiologists via phone or through the secured email system embedded into EARS. In addition, the families and PCPs are contacted by phone and letter with documentation of the activities entered into EARS. As described with the EHDI Parent Consultants, EARS continues to notify the EHDI Follow-up Coordinator at predetermined intervals until hearing status is confirmed, the family refuses the recommended follow-up, or the family becomes unresponsive to the attempts to assist them. When permanent hearing loss is reported on a DAE form, an additional alert is created. The form is reviewed by the EHDI Follow-up Coordinator and the clinical audiologist is contacted if any questions arise. Once hearing loss is confirmed, the Follow-up Coordinator processes the EARS alert and sends tool kits to the parents and PCP, refers the child to First Steps early intervention and notifies the Guide By Your Side program that a newly diagnosed child has been identified.

The Guide By Your Side (GBYS) parent program coordinator and outreach coordinator are notified through EARS to contact families via phone and assist the families in connecting with appropriate early intervention resources and additional resources offered in Indiana and across the country. If the family is reached by phone and agrees to participate in GBYS, the matched to an appropriate guide. Typically, families are matched to a GBYS parent guide in the same geographic region, however, some families are matched to a guide based on the language spoken at home (English, Spanish or ASL) or the type of hearing loss a child may have (permanent

conductive hearing loss, bilateral hearing loss, or unilateral hearing loss). The appropriate GBYS Parent Guide is specified on the EARS “Outcomes” form and the Parent Guide is notified through the EARS email system that a new family has been referred.

The GBYS Parent Guides have a limited view that enables them to automatically receive referrals for families who opt into the GBYS program. The limited view called the Outcomes form provides basic information about a given child and family. The form enables the Parent Guides to indicate information about technology usage, early intervention services, and other recommended services. It also provides a notes section where ongoing information related to direct parent-to-parent support can be documented.

The above description of the EHDI follow-up process as designed in Indiana was provided to demonstrate the complexity of the work that is done on a daily basis. With the support provided by the Centers of Disease Control and Prevention, the Health and Resources Services Administration, and the Indiana State Department of Health, Indiana EHDI has continued to observe good progress toward meeting the EHDI program’s 1-3-6 goals. One method of evaluating our progress is by monitoring the annual data submitted to the CDC. A summary of the data that was completed and submitted to the CDC in February 2013 for the 2011 Annual Survey is included in Attachment C. While data for children born in 2012 cannot be finalized at this time, preliminary data is presented below which supports continued progress toward timely confirmation of hearing status.

2012 Indiana EHDI Statistics*

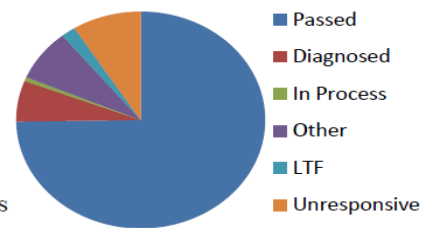
*Preliminary Data Submitted to CDC February 27, 2014

Total Births (N=85,103*)

Total Screened	82,192	96.57%
Total Passed w/out Risk Factors	79,153	96.3%
Total Passed with Risk Factors	675	0.8%
Total Did Not Pass	2,364	2.9%

Final Status of Children Who Did Not Pass UNHS (N=2,364)

Passed/Normal Hearing	1,766	74.7%
Diagnosed Hearing Loss	145	6.1%
In Process	15	0.6%
Other (Died, Moved, Refused)	181	7.7%
Lost to Follow-up (Unable to Contact)	46	1.9%
Parents Contacted but Unresponsive	211	8.9%



** 31.7% of diagnosed children had unilateral (one sided) hearing loss

B. Goals and Objectives:

Goals and objectives for this grant period are centered on enhancement of data quality, improvements in data collection and management, timely tracking and follow-up of babies, promotion of EHDI among professionals and parents.

Goal 1) Develop and maintain the EHDI-IS to accurately identify, match, and collect data that is unduplicated and individually identifiable through the EHDI process.

Goal 2) Collect and report individualized demographic data (as defined in HSF Survey) for every occurrent birth about the child's status and progress through the three components of the EHDI process.

Goal 3) Utilize findings from the analysis of EHDI data to guide the development and enhancement of the EHDI-IS and educate stakeholders about the program's successes, challenges, and future opportunities.

Goal 4) Strengthen EHDI-IS by developing and implementing an evaluation plan and utilize findings to improve the system.

Summary:

The Indiana EHDI program has made continuous progress during this grant period (July 2012 to June 2013). Even with staff and organizational changes, the procedures developed within the EHDI program over the last five years enabled EHDI staff to continue to provide consistent support to families of children in need of follow-up from newborn hearing screening and children diagnosed with permanent hearing loss. As the EHDI program transitions programmatically and physically from the Genomics and Newborn Screening Program to the Center for Deaf and Hard of Hearing Education (CDHHE) challenges will arise but possibilities for significant improvement for Indiana are at hand. It is the CDHHE's long-term vision that the services developed within Indiana can serve as a model for serving children with other chronic health conditions as well as for other EHDI programs across the country. The support provided by the CDC EHDI team, as well as, the financial support received by the CDC continues to be greatly appreciated and is crucial to the ongoing success of the Indiana EHDI program.