Iowa's Early Hearing Detection & Intervention Program

PROJECT NARRATIVE

INTRODUCTION

The Iowa Early Hearing Detection and Intervention (EHDI) program's mission is to ensure that all newborns and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, medical intervention and family support.

Iowa's EHDI program is making significant advancement toward assuring that all children in the state with hearing loss are identified, referred and receive timely and appropriate services and family support. The time between screening to diagnosis and age when early intervention (EI) and family support is provided has improved greatly, thereby minimizing delays in speech, language and cognitive development. This allows each child the opportunity to reach their full potential. Providers are more focused on early childhood communication milestones and in determining the root cause of a refer (did not pass) on a hearing screen or developmental delays as the child gets older. The EHDI program understands this goal cannot be fully realized without a comprehensive EHDI Information System (EHDI-IS) and statewide infrastructure. The Centers for Disease Control and Prevention (CDC) EHDI cooperative agreement and the Health Resources and Services Administration (HRSA) EHDI grant provides an organizing framework and core resources which are essential to advancing the state system. Iowa has a system of coordinated leadership and partnerships to accomplish the aims and objectives of the EHDI program. The purpose of this application is to describe Iowa's plans to further develop a sustainable system of care for newborns and toddlers so that children with hearing loss are identified early and receive appropriate services which will promote healthy child development. This application summarizes the strengths and accomplishments of Iowa's program, and outlines needs still to be addressed in creating a sustainable EHDI System of Care (EHDI SOC). An acronym guide is provided in Attachment 9.

Background

Significant accomplishments of Iowa's CDC EHDI program over the last decade are outlined below.

1) **State Legislation.** Iowa's legislation for newborn hearing screening provides solid infrastructure for reporting, surveillance and follow-up. Effective January 1, 2004, the Iowa code (http://www.idph.state.ia.us/iaehdi/common/pdf/iaehdi_admin_rules.pdf) and administrative rules mandate that every newborn be screened for hearing loss prior to hospital discharge. The law further provides that any birthing hospital, birth center, physician, Area Education Agency (AEA), audiologist, or other health care professional is legally required to report to the Iowa Department of Public Health (IDPH): 1) the results of a hearing screen, rescreen, or diagnostic assessment 2) primary care provider (PCP) that will assume responsibility for the child and 3) risk factors associated with hearing loss for any child under age three. Subsequent technical amendments on November 11, 2009, further improved reporting requirements and timelines for reporting. Iowa's statute and code help ensure the EHDI program is receiving timely, accurate, and complete information on every Iowa birth through diagnosis of hearing loss and assists the program in follow-up. In turn, the data provided to IDPH EHDI through surveillance are used to guide system and policy development.

2) **Collaborative Efforts.** Collaborative relationships play an integral role in the success and advancement of Iowa's EHDI SOC. In collaboration with the state EHDI coordinator, the EHDI program audiologists monitor miss and refer rates in EHDI database to verify rates are within established ranges and offer assistance with training, equipment or other identified problems. They also provide guidance and expertise to audiologists on recommended screening and diagnostic assessment best practices.

A contract is in place between IDPH EHDI and the Iowa Department of Education, Early ACCESS (EA) program (IDEA, Part C) for child find activities. These activities include a small amount of financial support for education, training and data sharing which includes early intervention referral and enrollment data, and technical assistance to AEA audiologists regarding EHDI best practices and reporting requirements. Through EA, AEAs provide hearing rescreens, referral for medical or diagnostic assessment and early intervention. IDPH's EA liaison is co-located within the Bureau of Family Health (BFH) where the IDPH EHDI staff is housed.

Iowa EHDI partners with the Iowa Leadership in Neurodevelopmental and related Disabilities (ILEND) program. ILEND is an interdisciplinary training program within the Center for Disabilities and Development at the University of Iowa. ILEND trainees contribute to the IDPH EHDI program by developing materials for parents, helping with data entry of audiological assessments, participating in the training of hearing screeners, and assisting with EHDI conference planning.

The IDPH EHDI program collaborates with the Center for Congenital and Inherited Disorders (CCID), which administers Iowa's birth defects registry, newborn dried bloodspot screening program, newborn critical congenital heart disease screening and is also located in the BFH. The IDPH EHDI program and CCID have an informal agreement that addresses data sharing between the two programs. Both programs share data to assist in follow up and to conduct a preliminary analysis of parental refusals.

IDPH EHDI has developed close working relationships with Iowa hospitals, birthing centers, EA, AEAs, and other audiologic assessment providers to facilitate statewide compliance with mandatory newborn hearing screening laws.

At the national level, Iowa EHDI was selected as one of two states to participate in the individual EHDI (iEHDI) pilot project through CDC from 2010-2012. Iowa was recognized by CDC at the conclusion of the pilot project as being a leader in the collection and analysis of high quality screening and follow up data.

3) **Web-based Surveillance System.** Iowa's EHDI surveillance system reflects state-of-the-art software technology and programming. IDPH contracts with Optimization Zorn Corporation (OZ Systems) of Arlington, Texas for its web-based surveillance software system, eScreener Plus (eSP™). Through the eSP™ surveillance system (EHDI database), the Iowa EHDI program is able to accurately identify, match, collect and report unduplicated and individually identifiable data on all occurrent births through early intervention referral and enrollment. The system is able to track all birth screenings through audiological assessment, follow-up activities when infants

do not move on for further screening or diagnosis, and early intervention referral and enrollment follow-up. All follow-up efforts are tracked through a case management module (CMM) developed by the EHDI program. This module helps the program evaluate its programming.

4) **Protocols.** The Iowa EHDI Best Practices Manual was developed in 2008 and is available on the Iowa EHDI website, www.idph.state.ia.us/iaehdi/common/pdf/best_practices_manual.pdf. The manual includes protocols, policies and procedures which provide consistent standards for facilities and audiologists responsible for hearing screening and diagnostic reporting. These documents address issues such as personnel, facility responsibilities, test parameters and follow-up procedures, parent refusals and confidentiality. IDPH EHDI has additional protocols related to quality assurance and lost to follow-up (LTF) or lost to documentation (LTD). Lost to follow-up is defined as infants that do not return for recommended screening or diagnosis after attempts have been made to reach the family by the EHDI program or child's primary care provider. Children lost to documentation are those children that may have had a hearing screen/assessment, but whom the EHDI program has no documentation of results, even after follow-up with the provider. In Iowa, both children are marked as lost after follow-up protocols are completed.

5) **Quality Assurance.** IDPH EHDI personnel regularly perform quality assurance activities within the EHDI database to ensure data accuracy and completeness. Quality assurance activities are completed weekly and monthly including vital records match, hospital confirmation for missing infants or infants with missed birth screens, identification of incomplete data fields, requests for birth screens for children transferred out of state and merging duplicate records.

6) **Program Evaluation.** Iowa's EHDI program has been using program evaluation to identify gaps in the EHDI SOC that can be addressed through policy and programmatic changes. A program evaluation steering committee has guided the evaluation process since 2009. The Iowa EHDI Advisory Committee members review the evaluation components to assess program progress and guide plans for programming and sustainability. During the next three years, Iowa will continue to incorporate continuous quality improvement methodology learned by the Iowa EHDI SOC team during participation in the National Initiative for Children's Healthcare Quality (NICHQ) training.

7) **Designated Follow-up Coordinator.** Iowa's EHDI program hired a follow-up coordinator in 2010 to perform follow-up activities for all children missed or who did not pass their birth screen. This individual contacts families and primary care providers to reinforce the importance of timely follow-up and provide guidance about local resources. This strategy led to a 24 percent decrease in the number of children lost to follow-up/lost to documentation between 2009 and 2011.

Program aims (goals) and aim objectives developed for this project are consistent with Healthy People 2020 Objective, ENT-VSL: Increase the proportion of newborns that are screened for hearing loss by no later than age 1 month, have audiologic evaluation by age 3 months and are enrolled in appropriate intervention services no later than age 6 months. The Iowa EHDI program will accomplish the following aims:

1) All infants born in Iowa will receive a hearing screen and rescreen (for those that did not pass the birth screen) no later than one month of age.
2) All infants who do not pass their birth hearing screen will receive reliable and timely audiological evaluation no later than three months of age.
3) All infants diagnosed with a permanent hearing loss will be enrolled in early intervention and family support no later than six months of age.
4) Families and providers are educated in a way that is culturally and linguistically competent to enhance their understanding and engagement in hearing screening, diagnosis, early intervention and family support.

Aim objectives and activities for each goal can be found in Attachment 1: Work Plan.

NEEDS ASSESSMENT

Demographics

Iowa is a rural state with approximately 3.06 million people according to the IDPH Bureau of Vital Statistics. With the continuing shift from rural areas to urban areas, more than half of Iowa's 99 counties are expected to decrease in population. However, Iowa's overall population increased by 2.6 percent from 2000 to 2009.

According to the 2011 census estimate results, Iowa's population continues to get more diverse. The state is 91percent White; however, racial and cultural diversity is increasing. The residents of Hispanic origin are the fastest growing ethnic group. The Hispanic population increased from 2.8percent in 2000 to 5.0 percent in 2010. In 2000, live births to Hispanic women made up 5.6 percent of all births, double the population proportion in the same year. This ratio continued in 2008 (8.2% vs. 4.2%). Approximately 240,041 children are birth to five years old and make up about 8.0 percent of the total population. Of these children, 8.9 percent are of Hispanic origin. There is another estimated 8.9 percent of children who have a special health care need.

Even with the influx of new citizens, Iowa's total population is projected to experience only modest growth between now and 2015. While the overall population remains stable, the minority populations are expected to grow in both absolute numbers and total proportion of the population. Other key demographic data that paint the picture of Iowa includes 32 percent of families are single parent families, 14.2 percent of poor families have children, 17 percent of adults are without a high school diploma and 82.4 percent of fourth graders demonstrate reading at a proficient level.

Although the Hispanic community in Iowa is growing, diversity shows less variability in the numbers of children LTF/LTD based on maternal demographics data. In Iowa, LTF/LTD rates were highest among mothers who:

- Were between the ages of 21 and 29
- Were American Indian/Alaskan Native and Hispanic
- Had less than a high school education
- Paid for the delivery on their own (typically Amish and home birth families)

LTF/LTD rates were analyzed by selected demographic variables including maternal age, race/ethnicity, education level and the source of payment for delivery of the baby. The percentage of infants lost to follow-up in each category is shown in Table 1 below.

Mother's Education Level	2010	2011	Race/Ethnicity	2010	2011
Less than HS	8.40%	7.00%	White	1.10%	0.80%
High School/GED	1.40%	1.00%	Black	1.30%	1.40%
Associate or Bachelors	2.20%	1.90%	American Indian/Alaska Native	1.90%	2.10%
Masters	0.50%	0.50%	Hispanic	1.60%	1.20%
PhD	0.10%	0.50%	Other Races	1.10%	0.95%
Mother's Age	**2010**	**2011**	**Payment Source**	**2010**	**2011**
12-20 years	13%	3%	Private Insurance	0.04%	0.30%
21-29 years	52%	45%	Medicaid	1.60%	1.10%
30-38 years	31%	44%	Self-Pay	9.80%	8.60%
39-48+ years	5%	8%	Other, unknown	2.80%	1.40%

Table 1: Lost to Follow-up Rates by Maternal Demographics: IA EHDI, 2010-2011

Target Population

The target population for newborn hearing screening is all occurrent births in Iowa. The annual birth rate is approximately 40,000 per year. Targets for this project are infants (approximately 2,400 annually) who referred or missed the initial screen and are in need of additional testing. The target populations for referral to early intervention services are those infants identified with hearing loss, which is between 60 and 80 per year.

Identified Need Areas

In September 2013, the Iowa EHDI personnel met and worked through the NICHQ driver diagram to explore possible strategies that were needed to build upon program successes and that would address areas of need within the EHDI SOC. During this meeting, program data and quality improvement initiative results were reviewed by the members. The EHDI team then engaged the EHDI Advisory Committee members in a similar group activity at the quarterly meeting held on October 4, 2013. Committee membership is included on page 16. Committee members provided the EHDI team with additional feedback on future strategies to decrease the numbers of children LTF/LTD and helped prioritize the aims, aim objectives and strategies to build upon existing infrastructure and capitalize on provider partnerships.

Prioritization of the activities was based upon resources and perceived ability to make the biggest impact (e.g. financial means, time, and personnel) on decreasing the numbers of infants LTF/LTD and improve timely referral and enrollment in EI services.

Over the last two years, the state EHDI coordinator and follow-up coordinator have completed an extensive amount of analysis on individually identifiable EHDI data for all occurrent births

for 2010, 2011 and 2012 (preliminary). EHDI personnel have reviewed data to determine if the Iowa EHDI program is meeting the national goals of screened no later than one month, diagnosed no later than three months and enrolled in early intervention no later than six months of age as a part of the CDC iEHDI project and in preparation for the annual CDC survey. Some of the results of the analysis and need areas are summarized below.

Improving Timely Follow-up through Partnerships

Of the total occurrent births in 2010 and 2011, approximately 40 percent were reimbursed by Medicaid based on the linkage of Medicaid claims data to the birth certificate. In 2010, 22percent of the infants on Medicaid that needed an outpatient hearing screen were LTF/LTD as compared to 16 percent in 2011. Upon further analysis, the EHDI program found 45 percent of the infants needing hearing screening follow-up were being served in the Women, Infants and Children (WIC) program. In an effort to reduce LTF/LTD among these families, the EHDI program reached out to the Title V/WIC/Home Visiting (HV) programs in the fall of 2013. Collaborative efforts exist between the BFH where the EHDI program resides and the Bureau of Nutrition and Health Promotion where WIC resides. These programs work closely to share data, refer participants to other health care agencies, and support collaborative efforts. Making referrals for children who need additional hearing screening or follow-up is already a part of their mission and does not require a recruitment plan and alerting Title V/WIC to the children in need of hearing screening/assessment follow-up is allowed by Iowa EHDI administrative code. These programs have agreed (see Attachment 4) to develop protocols for data sharing which will trigger follow-up by the Title V/WIC/HV program for children identified as needing further hearing follow-up. The plan is outlined under Aim 1, Aim Objective 1.4.

Improving Use of Best Practices and Decreasing Refer/Miss Rates

Another need identified upon review of the LTF/LTD data is in relation to refer and miss rates in Iowa birthing facilities. In 2010 and 2011, there were 38,572 and 38,039 total births respectively. The average screening rate for birthing facilities (n=81) in Iowa has been 99 percent for the last six years. The miss rate averages 1 percent. Hospitals report the misses are a result of early discharge at the request of the families (e.g. Amish). While the screening rate is very positive and shows a commitment to hearing screening, the number of infants that refer on their birth screen presents a challenge. Hospital refer rates have averaged 6 percent for the last six years with the majority of the hospitals using otoacoustic emissions (OAE) equipment averaging 12 percent and hospitals using automated auditory brainstem response (AABR) equipment averaging three percent. This number has remained consistent even though hospitals wait the recommended 24 hours before performing a hearing screen and rescreen prior to hospital discharge. The number of infants that pass the outpatient hearing screen when using OAE equipment averages 75 percent therefore it is believed that the higher the refer rate at birth can be attributed to the large numbers of birthing facilities using OAE equipment in the rural communities. Due to higher refer rates and the small number of diagnostic assessment facilities (n=5), the Iowa EHDI program recommends all infants receive an outpatient hearing rescreen prior to being referred to a pediatric audiologist for a diagnostic assessment.

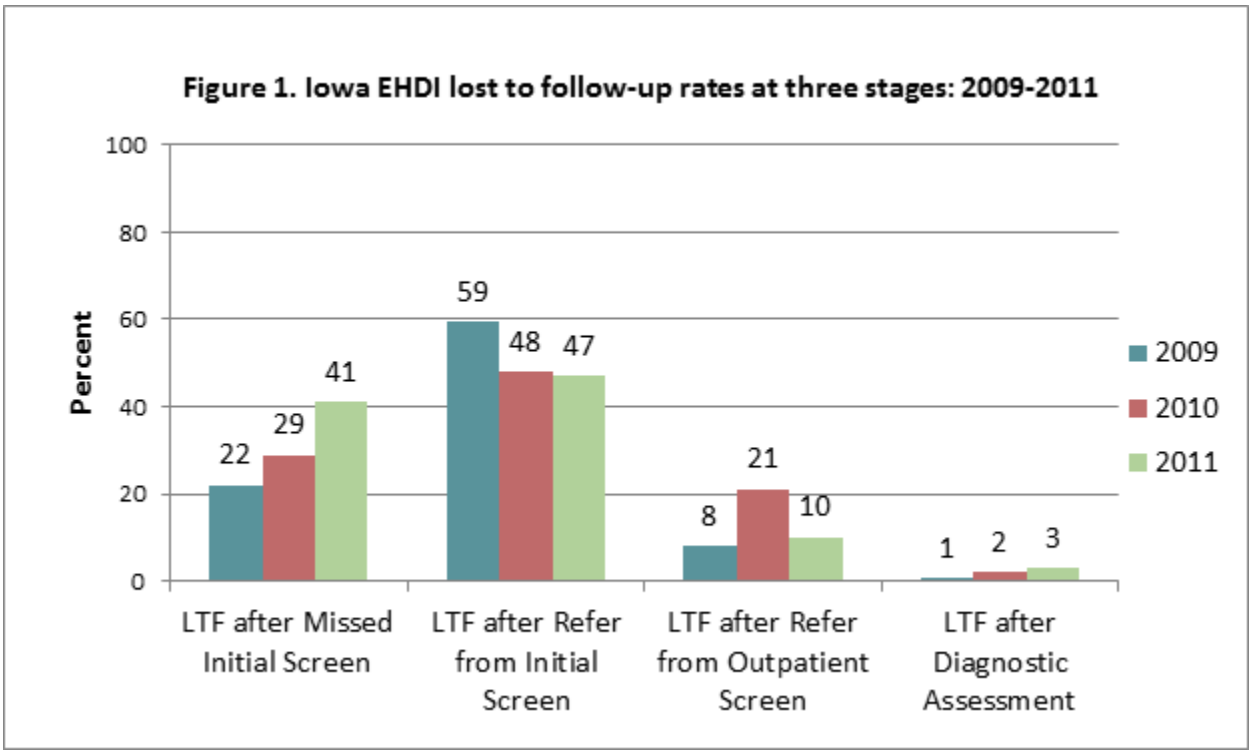
The EHDI program is currently in the process of completing an analysis of birthing facility outcomes based on equipment type. Level II birthing facilities have made significant progress in

decreasing refers rates in the last year and a half, refer rates that were once in the mid-teens have dropped to single digits. The decrease can be attributed to the purchasing of AABR equipment by the five birthing facilities that previously used OAE equipment. The use of AABR equipment by these facilities has led to a decrease in the number of infants needing follow up which leads to fewer children being LTF/LTD. The results of the analysis will be shared with birthing facilities in hopes of encouraging hospitals to explore the purchase of AABR equipment to perform hearing screens as a way to improve screening outcomes and decrease the numbers of infants LTF/LTD. The analysis will assist in preparation of the activities included under Aim 1, Aim Objective 1.1.

Another strategy used by the EHDI program to improve the use of best practices and screening rates was to disseminate quarterly reports to communicate birthing facilities compliance with EHDI law and best practices for the past two years. This strategy has resulted in mixed results. Some hospitals have used the reports to identify need areas which then led to modified protocols, additional training and quality improvement goals while others have not given the reports any noticeable attention. The EHDI program is planning to take the reports a step further and develop a ranking system to help improve compliance in meeting state and national EHDI goals. The birthing facility will see where they stand in comparison with other birthing facilities with the same classification.

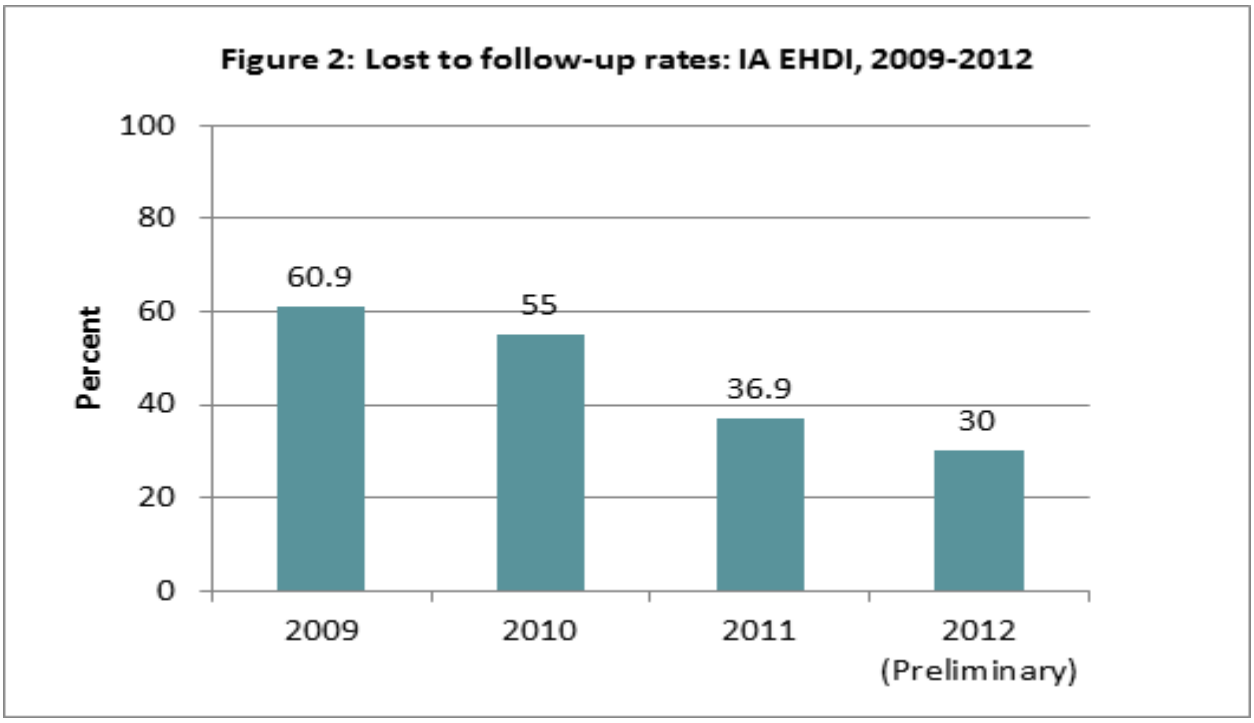
Improving LTF/LTD through Increased Outreach and Designated Follow-up Coordinator

Figure 1 below shows the number of infants LTF/LTD before they receive a birth screen and diagnostic assessment for years 2009-2011. It is important to note the number of children LTF/LTD prior to birth screen are almost exclusively home births. The number of home births in Iowa has increased in the last five years. While home births only make up 1 percent of Iowa's total births, they continue to present a challenge for Iowa's EHDI SOC. Although outreach to these families has increased significantly, the number of families that refuse the hearing screen remains high. In 2010, 76 percent of 452 home births were marked as refused or LTF/LTD. In 2011, the number of refusals increased by 5 percent. In 2012, EHDI program personnel anticipate the outcome for home birth infants will improve due to additional outreach efforts including: personal phone calls (EHDI program partnered with IDPH vital records program to obtain phone numbers); a screening program that was established in one Amish community; and a concerted education effort targeted at nurse midwives (Aim 1, Aim Objective 1.3).



Factors that contributed to lowering the LTF/LTD rate are as follows: hiring a follow-up coordinator; performing weekly quality assurance activities; conducting hospital site visits; and working with the IDPH Bureau of Vital Statistics to obtain the list of occurrent births to ensure all infants are accounted for in the EHDI database and performing follow-up activities with families in a timely manner.

Prior to 2010, referrals were made to regional early intervention programs; audiologists and their support staff attempted to reach families and schedule appointments for children who missed or referred their birth screen. These programs only reached out to the parents due to confidentiality rules. The programs had to refer all inquiries with screening result discrepancies back to the EHDI program for follow-up with the hospitals, therefore delaying timely follow-up. That year Iowa's LTF/LTD rate was 55 percent and in 2009 it was 60.9 percent. A follow-up coordinator was hired in 2010. This individual began making calls to both parents and the infant's PCP if the infant did not return for an outpatient hearing screen. During the call, education was provided to parents, physicians and physician nurses on the importance of timely rescreen, follow-up and referral. This helped decrease our LTF/LTD rate from 60.9 percent in 2009 to 36.9 percent in 2011 which is a 24 percent decrease in two years (Figure 2). This accomplishment was recognized by the CDC EHDI data program lead. Based on our preliminary analysis of 2012; we anticipate our LTF/LTD rate will be reduced to approximately 30 percent.



Another activity that led to a decrease in infants LTF/LTD was site visits to all birthing facilities. The visits were conducted by the state EHDI coordinator, EHDI audiology technical assistant and a parent, when available. The EHDI coordinator requested each birthing facility complete a rubric prior to the visit. The rubric is a self-evaluation tool of progress in meeting EHDI law, rules and best practices. At the site visit, the coordinator reviewed hearing screening and follow-up data, protocols for the birth facility, best practices and the facility's rubric. Birthing facility personnel heard from a parent of a child with a hearing loss about their experiences and the importance of timely follow-up. Following the site visit, each facility received a detailed report that outlined their screening and follow-up rates, strengths, areas for improvement and resources available to assist them in making changes. Visits were well received as evidenced by positive feedback and high satisfaction (95% reported the visits were helpful, 4.8% marked neutral) on the EHDI Site Visit Survey sent to the birthing facilities following the visit. The EHDI Program determined through analysis of refer and miss rates that hospital site visits positively impacted the rates. Sixty-nine percent of the birthing facilities that received a hospital site visit decreased their refer rates following the visit date. Some hospitals have maintained a lower refer rate while other hospitals refer rates have begun to slowly increase over time. There were other positive changes such as increasing the number of hospitals that assist families with scheduling a follow-up hearing screen prior to hospital discharge, replacement of old OAE equipment, and improved reporting of results to the infant's primary care provider.

Currently, Iowa is exceeding the national goal of infants screened for hearing loss no later than one month. In 2011, Iowa's screening rate was 98.4 percent compared to the national average of 94.9 percent. It's important to note that the totals in Table 2 include infants missed on their birth screen. The percentage of infants diagnosed by three months of age increased from 72.8 percent in 2010 to 76.7 percent in 2011 (Table 2). Although Iowa EHDI is above national average for

screened and diagnosed by 1 and 3 months respectively, it is considerably lower (50%) than the national average of 64.2 percent on the third goal of having all infants with permanent hearing loss enrolled in early intervention services no later than six months of age. This percentage may increase in the future as IDPH EHDI has recently been given access to referral and enrollment data for EI. In 2010, 2011 and the first part of 2012, early intervention data was withheld because Part C was not mandated to report early intervention data to EHDI. Barriers that may have played a role in the slight change in numbers of infants diagnosed by three months of age and enrolled in early intervention by six months of age are as follows:

- Inadequate staff because of high turnover in EHDI follow-up personnel (designated to do follow-up for infants who do not pass their outpatient hearing screen).
- Limited number of pediatric audiology clinics (5) who make a diagnosis of hearing loss.
- Untimely referrals by physicians ("taking a wait and see approach").

While the numbers of infants meeting the 1-3-6 goals in Figure 2 only showed slight improvement, the totals of infants LTF/LTD improved significantly from 55 percent in 2010 to 36.9 percent in 2011.

	2010		2011	
Total Births	38572		38039	
	Number	Percent	Number	Percent
Screened no later than 1 month	37452	98.3%	36903	98.4%
Diagnosed no later than 3 months	1730	72.8%	1751	76.7%
Early Intervention no later than 6 months	37	50%	25	50%

Table 2. Summary of 1-3-6 goals; IA EHDI, 2010-2011

Improving the Timeliness of Diagnostic Assessments through Use of Tele-Audiology

Over the last two years, Iowa EHDI piloted the use of diagnostic tele-audiology services in an effort to improve timeliness of diagnostic assessments. In 2013, remote testing diagnosed one child with a permanent hearing loss. However, the use of tele-audiology services has been very limited due to the low numbers of referrals. Since the summer of 2013, EHDI follow-up personnel have been searching the database to identify infants up to 6 months of age who might be candidates for diagnostic tele-audiology. If an infant is in need of a diagnostic assessment, the EHDI follow-up coordinator contacts the infant's PCP to make a referral. In September 2013, area providers were sent a letter to increase their awareness of tele-audiology services that could be used locally to provide access to diagnostic audiology evaluations for infants that did not pass their outpatient hearing screen. Next steps include continued testing of the technology to see if it can be successfully implemented in other geographic areas using regional educational audiologists.

METHODOLOGY

The Iowa EHDI program will build upon the accomplishments and resources the EHDI SOC has established over the last ten years. Iowa's EHDI program has been using program evaluation methodology as a tool to identify gaps in the EHDI SOC and address these gaps through education, outreach, policy and programmatic process changes.

A program evaluation steering committee, quality improvement team (QI), and the EHDI Advisory Committee has guided the evaluation process in Iowa since 2008. The QI team leads the process and utilizes quality improvement methodology learned through participation in the NICHQ learning collaborative. This methodology is used to accelerate the programs activities and result in meaningful change. The Iowa EHDI Advisory Committee reviews the evaluation components to assess program progress and guides plans for additional programming to work towards sustainability. The QI team is made up of the following individuals: parent of a child who is deaf, Iowa EHDI coordinator, EHDI follow-up coordinator/program evaluator, pediatric audiologist (hospital and educational based), state genetics coordinator, Iowa EHDI Chapter Champion (depending on availability) and a representative from the early intervention program. Because of limited resources and the fact that these individuals have the greatest expertise with the EHDI database, the follow-up coordinator and state EHDI coordinator also serve in the capacity of program evaluators. Other QI members are added based on the nature of the improvement initiative. For example, if the EHDI team is trying to decrease refer rates in birthing facilities, the EHDI contact at the birthing facility, which is typically a nurse manager, then becomes a part of the team.

The following are a few evaluation activities completed by the EHDI QI team over the last several years. This will provide insight into experience and how lessons learned were used to guide system improvements and as a resource to help prioritize activities included in the current work plan (Attachment 1). In 2010, the IDPH EHDI coordinator and follow-up coordinator worked with CDC personnel on evaluation planning and development of evaluation tools for Iowa EHDI. A logic model (Attachment 8) was developed and has been used to guide program evaluation and future program development. The logic model depicts the problem, inputs, activities, outputs, outcomes and impact. As shown in Attachment 8, the primary program methodologies include what we invest, what we do, products of our activities and end results.

IDPH EHDI staff, in conjunction with the Iowa EHDI Advisory Committee, completed a prioritization process at that time and identified the following areas to be evaluated: surveillance, referral processes and family communication related to newborn hearing screening and follow-up. Various evaluations of the program were completed including a parent survey, database survey and a physician survey.

Database Surveillance Survey

A database surveillance survey was finalized in August 2010 and completed by EHDI database users in September 2010. Analysis was completed in October 2010 and preliminary results shared with the EHDI Advisory Committee in October 2010 and January 2011 (see http://www.idph.state.ia.us/iaehdi/advisory_committee.asp Iowa EHDI Advisory Committee meeting minutes). Overall, 80 percent of respondents strongly agreed that the EHDI database was easy to use to capture screening and assessment results for children under the age of three. A few suggestions were made by respondents which have since been incorporated into the database when funding was available for a software upgrade.

Parent Survey

A parent survey was mailed in April 2011 to parents of children born between July 1 and December 31, 2010, to assess their knowledge and experiences of newborn hearing screening and follow-up. It was designed as a phase of program evaluation to help the EHDI program identify areas of strength and determine areas that need improvement based on family experience. CDC worked with the EHDI program to develop the survey. There were 1913 surveys mailed to families whose infants were born in a birthing facility and 218 mailed to home birth families. A total of 264 (12%) surveys were completed and returned to the Iowa EHDI program and 113 surveys were returned as undeliverable. Seventy-five percent of parents of infants born in a birthing facility indicated they had knowledge of the hearing screen prior to their infant's birth, while only 32 percent of home birth families indicated they were aware of newborn hearing screening. This was an increase from a survey done in 2007. Only a few of the infants born at home received a hearing screen according to survey results. When asked why they chose not to have their infant screened, the parents responded:

- Personal beliefs (21%)
- Did not think it was important (25%)
- Believed their infant was not at risk for a hearing loss (36%)
- Healthcare provider said their infant was not at risk (3%)

Other comments included they did not think it was necessary or it was inconvenient. In regards to outpatient screening assistance, 80 percent of the parents responded they were told their infant needed an outpatient hearing screen and they understood the information with 55 percent reporting the birthing facility assisted them with scheduling the appointment.

Some of the other areas explored on the survey included the timing of the presentation of educational brochures, results, who delivered the results, and early intervention and family support referrals. The results of the survey were shared with Iowa EHDI Advisory Committee Members in October 2011. They were also used during hospital site visits to reinforce best practices in screening, communication of results and timing, risk factors and scheduling of hearing rescreen appointments prior to hospital discharge (Aim 1, Aim Objective 1.2).

Physician Survey

In the fall of 2012, the Iowa EHDI program partnered with the National Center for Hearing Assessment and Management (NCHAM) to survey Iowa physicians about their knowledge, attitudes and beliefs regarding newborn hearing screening and follow-up. The purpose of the physician survey was to understand the degree to which medical homes are engaged within EHDI systems; have an understanding of physician attitudes and knowledge regarding newborn and early childhood hearing screening and follow-up; and to identify strategies to support physicians in their role in EHDI. A hard copy of the survey was sent to a randomized sample of PCPs assigned to an infant in the last year in the Iowa EHDI database. The PCP included physicians, Ear, Nose and Throat (ENTs), physicians' assistants, and advanced registered nurse practitioners.

The letter also included a hyperlink for PCPs that wanted to respond to the survey online. A postcard reminder was mailed 7-10 days later. Of the 925 surveys mailed, 6 surveys were returned as undeliverable; only 76 (8%) surveys were returned. Other states that participated in

this effort had similar response rates. Only two surveys were completed online for Iowa and this was also consistent with experiences of other state EHDI programs.

Lessons learned included difficulty obtaining PCP emails; many providers expressing an unwillingness to communicate via email due to the large volume of emails received each day; online option is still not perceived as a primary mode of communication for a majority of PCPs; PCPs report being inundated with surveys; and only a small number of PCPs expressed an interest in receiving the results. Although PCP knowledge of newborn hearing screening and follow up has improved when compared to the last survey completed in 2005, the survey showed there is still work to be done. It is important to note that Iowa's averages were similar to the national averages or slightly above in terms of physician knowledge, beliefs and attitudes.

Iowa American Academy of Pediatrics and Iowa's EHDI program formed a Medical Home Implementation Team to accelerate the use of evidence based recommendations by the Joint Committee on Infant Hearing (JCIH) and developed a toolkit containing resources about hearing health. QI methodologies including the use of Plan-Do-Study-Act (PDSA) cycles were used to determine the information needed by PCPs, and their preferred format. Feedback was used to develop the EHDI Medical Home Toolkit. Toolkits were mailed to 605 PCPs at 112 physical addresses covering 77 percent of all Iowa births. Additionally, all otolaryngologists received a targeted toolkit as did every birthing facility. Initial feedback to the toolkit by physicians has been disappointing and despite numerous attempts, response to follow-up surveys has been very low. A small phone survey was undertaken to compare if PCPs who had children recently diagnosed with hearing loss would have better recall of the kits compared to PCPs without children recently diagnosed with hearing loss. Only 6 percent of those PCPs surveyed with a child in the practice with hearing loss recalled receipt of the toolkit but they had not opened the kit.

Promising Change Strategies

The Iowa EHDI program used the PDSA improvement model to test changes, quickly identify promising ideas and build confidence with providers that the changes would lead to improvement. The following paragraphs pertain to promising strategies identified through the NICHQ learning collaborative for reducing LTF/LTD among EHDI programs and how they were implemented into the Iowa EHDI SOC.

Scripting the screener's message to parents: The EHDI program designed a tool for communication and tips for successful screening that was sent to all birthing facilities in the summer of 2010 to reinforce best practices in existing protocols. The tool was first piloted in two birthing facilities; one in an urban setting and another one in a rural setting. Both hospitals covered the contents of the tool in a staff meeting. The feedback was positive and both hospitals expressed interest in using the tool for training. Both facilities agreed to post the laminated tool in the area where hearing screens were performed so the tool could be referenced, as needed. The Iowa EHDI coordinator contacted them after a month to discuss their ongoing use of the tool. Again, the feedback was positive. The program then sent the communication tool to the remaining birthing facilities. The remaining birthing facilities provided positive feedback to the

EHDI program after receipt of the tool. However, on hospital site visits, the EHDI coordinator found that only half of the nurseries had the tool in a visible location and knew what the coordinator was referring to when she inquired about its effectiveness. A lesson learned with this strategy was that the communication tool was successful in the beginning, but did not produce lasting results. Since then, the EHDI program has begun sending out emails to the birthing facilities on a quarterly basis to remind them of best practices related to communication with families. This will be evaluated in the first quarter of 2014 to determine usefulness.

Using FAX-back forms: In 2007, the EHDI program utilized FAX-back forms to communicate the next steps to PCPs for infants in their care. The FAX-back forms were rarely returned. The forms that were returned had incomplete information or results that the program already had on record. Please note the program had just begun communicating with PCPs and PCPs were not as familiar with their roles and responsibilities for children in need of necessary follow-up for a failed hearing screen.

In 2013, QI methodologies were used to develop and begin testing a revised FAX-back form to communicate with the PCP regarding infants in need of diagnostic assessments. The revised form was designed to educate PCPs about the "next steps" in follow-up and to serve as a reminder to the PCP to check back with their patient on the status of their referrals, if there appears to be no follow through. Compared to 2007 results, preliminary data show slight improvement. Faxing PCPs showed a response rate of 43 percent versus 36 percent for phone calls returned to EHDI during that same time period. Of the total faxes returned to EHDI, 32 percent provided new screening or assessment results not previously recorded in the EHDI database. If further enhancements to the database could be completed that allow direct messaging to providers, faxing could increase effectiveness and sustainability.

Ascertaining the name of the infant's primary care provider: In Iowa, birthing facilities are required by law to report the name of the infant's PCP. The rules were updated in 2009 to include the "PCP that will assume responsibility of the child upon discharge" to avoid being given the name of the attending/delivering physician. This action greatly improved reporting of the appropriate PCP. In addition, the EHDI assistant runs a report each month to ensure every infant has a PCP listed. If an infant is missing a PCP, the birthing facility is notified and instructed to add them to the record. This is a quality improvement measure that is highlighted in quarterly hospital progress reports.

Making rescreening and or audiology appointments at hospital discharge: Prior to hospital site visits in 2010, less than 65 percent of Iowa birthing facilities were providing outpatient hearing rescreens. The number of birthing facilities providing outpatient hearing screens in 2013 has increased by 15 percent. Of the remaining birthing facilities (n=15) that do not provide outpatient hearing rescreens, the majority are assisting families with scheduling appointments with other outpatient screening providers upon discharge. Aim 1, Aim Objective 1.2 is designed to spread the change strategy of scheduling hearing screen or assessment appointments prior to hospital discharge to the remaining birthing facilities not yet assisting families in scheduling.

Scheduling two audiology appointments two weeks apart at hospital discharge: Iowa has a protocol that recommends a hearing rescreen prior to referring an infant for diagnostic assessment. This is because Iowa has a very small number of pediatric audiology providers (n=5)

for infants and also, more than 75 percent of those infants in need of a hearing rescreen pass on their outpatient rescreen. Iowa EHDI has worked with hospitals and healthcare providers to stress the importance of timely rescreens, if infants do not pass the rescreens providers should assist the families in getting the infants scheduled for an unsedated diagnostic assessment. When Iowa EHDI approached diagnostic assessment providers about scheduling audiology appointments two weeks apart for infants, they declined citing scheduling issues. The EHDI program will explore this further if there is evidence within the data that proves there are delays because of full schedules (Work Plan Activity 2.1.4).

Streamlining the EI referral process: In the past, Iowa EHDI was not able to obtain the referral and enrollment dates for infants diagnosed with a hearing loss. To obtain these dates, the Iowa EHDI program worked with Iowa audiologists required to report screening and diagnostic assessment data to the IDPH EHDI program. Some educational audiologists and early intervention liaisons that worked with the EI programs agreed to share those dates to avoid duplication of referrals, while others refused to share information due to interpretation of Family Educational Rights and Privacy Act and Part C privacy regulations.

In the spring of 2013, the Iowa EHDI coordinator and EA liaison wrote a letter to the Department of Education (lead agency for Part C) attorney requesting permission to access referral and enrollment data for all infants suspected of or diagnosed with a hearing loss. The letter outlined research that showed evidence of data sharing in other states and referred to a document authored by NCHAM that addressed how this information may be shared among partnering Part C agencies. Additionally, the letter referenced in the most recent Memorandum of Agreement (MOA) between IDPH and EA which provides that signatory agencies shall share information, consistent with the law, and that the agreement specifically included EHDI. The attorney ruled that because: the MOA authorizes the exchange of EHDI information; child find rules require coordination with EHDI; and Part C law allows the exchange of this information among partnering agencies, it was determined there was no barrier in state or federal law to granting the request for the exchange of information. Since the ruling, the EHDI program has regularly received referral and enrollment data upon request.

Improving data tracking systems: Iowa EHDI database is able to accurately identify, match, collect and report unduplicated and individually identifiable data on all occurrent births through to early intervention referral and enrollment. In the spring of 2012, Iowa added a CMM which accurately documents each contact made with the infant's family, PCP, and other professional contacts including EA and family support referrals and enrollment. The CMM reports were developed to allow easy determination of the number of infants in need of follow-up, timeliness of their follow-up, and outcomes at each stage of the EHDI process.

Iowa's EHDI program is evaluated using a combination of process and outcome measures. For process measures, program progress towards meeting aims and aim objectives is tracked according to an established work plan and timeline. Outcome measures are assessed to determine the extent to which program activities promote the national EHDI goals.

EHDI Advisory Committee
The Iowa EHDI Advisory Committee was formed in 1994. This committee represents the interests of the people of Iowa and assists in the development of programming that ensures the availability and access to quality hearing healthcare for Iowa children. The EHDI Advisory

Committee typically meets in January from 9 a.m. until 12 noon using Iowa Communications Network and in April, July and October from 10 a.m. until 3 p.m. at a location in central Iowa. Committee membership is outlined in Iowa administrative rules, www.idph.state.ia.us/iaehdi/common/pdf/iaehdi_admin_rules.pdf. Membership includes representation from different facets of the health care community including the Iowa Hospital Association, private practice audiologists, pediatricians, family practice physicians and otolaryngologists. The committee also includes representation from the deaf community, parents of children with hearing loss, advocates, Early ACCESS (IDEA, Part C), Area Education Agencies, and other stakeholders that are affected by or involved with newborn hearing screening and follow-up. Membership is approved by the IDPH director. Each committee member is requested to serve a term of three years. Members may continue to serve longer at the request of the IDPH director unless their absence at meetings exceeds attendance policy.

Linkages to Other Child Health Programs
A few collaborative efforts were described in the background and needs assessment sections on pages two and six, respectively. Other linkages include partnerships with Early Head Start (EHS), WIC, Title V and Home Visiting outlined below.

Early Head Start
The Iowa EHDI program collaborated with the EHS program to pilot the NCHAM's Early Childhood Hearing Outreach (ECHO) Initiative in four Early Head Start programs across Iowa. The EHS pilot sites identified the following strengths: 1) a small number of children who were once identified as "lost to follow-up" have resurfaced and received a needed hearing screen; 2) EHS programs are using an objective method for screening infants and toddlers hearing; 3) EHS programs are following the ECHO project protocols which mirror Iowa EHDI protocols; 4) EHS programs are reporting the results to the IDPH as required by law which helps close the gap on children in need of follow-up; and 5) one program identified a child with a hearing loss.

Although initial collaborations have been successful with EHS specific challenges remain: 1) EHS families are often mobile and may not complete the follow-up recommendations for a child that did not pass before they leave the program; 2) there is a higher rate of children who did not pass the hearing screen due to otitis media and the child may linger "in process" because of treatment or lack of follow through; and 3) higher refer rates may be related to the skill level of staff. In the fall of 2013, an EHDI audiologist received training from NCHAM on the newly revised curriculum and recommended processes for EHS programs. One of the requirements of the training was for the audiologist to train two additional EHS programs within six months. Iowa EHDI has identified two EHS programs to train in the first quarter of 2014. The EHDI program will identify strengths and areas for improvement before recommending the use of OAE equipment in other EHS programs.

Title V

The Title V Maternal and Child Health (MCH) Block Grant is administered through the BFH, within IDPH. It allows IDPH to assure access to preventive and primary health care for mothers, infants, children, and children and youth with special health care needs. Part of their mission includes making referrals for children in need of health or community resources. Because of the diverse families that Title V serves, EHDI reached out to the program in the fall of 2013 to explore the development of an alert system for infants and children in need of a hearing screen to reduce the infants LTF/LTD. The Title V program has agreed to develop protocols for data sharing which triggers follow-up for children identified as needing additional hearing screen or an assessment.

WIC

WIC is a supplemental nutrition program for babies, children under the age of 5, pregnant women, breastfeeding women and women who have had a baby within the last six months. WIC helps families by providing healthy foods, nutrition, education and referrals to other healthcare agencies. On February 11, 2013, EHDI staff met with WIC personnel to facilitate a formal discussion about greater collaboration between the two programs. The meeting was held to explore the idea of WIC personnel assisting families in making appointments for children needing necessary hearing healthcare follow-up at WIC visits. Both programs felt this collaboration would benefit Iowa children and families. Iowa EHDI and WIC entered into a Memorandum of Agreement on February 22, 2013 which allows the exchange of data between the two programs. The programs made the decision to utilize the PDSA improvement model to test changes before statewide implementation to give the EHDI and WIC programs, parents and other stakeholders the opportunity to see if the proposed changes will work.

WIC will place an alert in their web-based data system for infants in need of further hearing screen/assessment. The WIC personnel will see the alert when the family comes for their WIC visit. The WIC program will stress the importance of follow-up, explore if there are barriers and assist the family in scheduling an appointment in their community. If the family refuses the hearing screen at either visit, the WIC program will ask the family to sign the EHDI refusal form. The signed form will be returned to the EHDI personnel for documentation in the EHDI database and the EHDI program will send a final letter to the family.

Home Visiting

The IDPH received a grant to administer the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program. The program is designed to improve Title V programs by strengthening activities for at risk populations through home visiting. In the fall of 2012, the Iowa EHDI coordinator met with MIECHV program personnel to explore a possible collaboration. Due to other MIECHV priorities (e.g. database development), specific activities related to assistance with locating infants and toddlers in need of a hearing screen/assessment were delayed. In the spring of 2013, the EHDI program partnered with MIECHV to conduct a webinar on newborn hearing screening and their role in assisting families in locating existing hearing screen and diagnostic assessment providers. The webinar also provided information about the responsibilities related to reporting if a MIECHV program is exploring the use of hearing screening equipment. The webinar covered the costs associated with the equipment,

protocols that would need developed and the partnerships that are required for a successful program. In the next grant cycle, EHDI will work with the MIECHV program to explore establishing a method to flag infants in need of further screening or assessment.

Our hypothesis is that collaboration with these programs will decrease the numbers of infants LTF/LTD and improve the timeliness of hearing screens/diagnostic assessments.

Sustainability

Iowa's newborn hearing screening legislation is an unfunded mandate; however, Iowa EHDI's SOC continues to produce significant results through integrated programming using braided federal funding. Iowa relies on funding from CDC, HRSA and the EA (IDEA Part C) to maintain and continually improve its comprehensive, coordinated EHDI system and work towards sustainability. The loss of federal funding would have a negative impact on infrastructure; follow-up; surveillance; and more importantly infants and children in Iowa. It would take the program back to a time when infants and children with a hearing loss were not diagnosed for months and in some cases year, therefore delaying early intervention and family support. There would be no personnel to ensure birthing facilities were providing universal hearing screens, manage the comprehensive database, ensure timely reporting and perform follow-up activities. As a result, data would be incomplete and in some instances, inaccurate leading to an increase in the number of infants and children LTF/LTD. Maintaining the program will require identification of other funding sources, as well as strengthening current partnerships. Outlined below are strategies being explored by EHDI program personnel to work towards a sustainable EHDI SOC.

In the spring of 2013, the EHDI program and CCID met to explore merging the individual databases, sharing outreach and educational opportunities and discussing funding opportunities that may assist with program sustainability (e.g. newborn screening fees). These programs put out a request for information for a software solution that will provide detailed screening management, referral tracking, data analysis and electronic health record interoperability and reporting for early childhood screening programs. Currently, multiple data systems exist within these programs, resulting in redundant work, lack of coordination and reduced data accessibility. The programs seek data integration for the following screening components:

- Early Hearing Detection and Intervention
- Newborn dried bloodspot screening
- Newborn screening for critical congenital heart disease

During the grant project period, EHDI will collaborate with Iowa Medicaid on proposals for payment reform to cover care coordination services to IDPH EHDI for Medicaid children with possible hearing loss. The EHDI program will at the same time explore reimbursement for tele-audiology ABRs. Funding would ensure sustainability of essential care coordination and follow-up services as well as support the use of tele-audiology for diagnosis. As tele-audiology becomes standard practice, it will help sustain the costs of the equipment and audiologists.

Furthermore, once educational presentations to pediatric residents and other healthcare providers becomes a part of routine training, providers will have an increased knowledge and awareness

about newborn hearing screening and follow-up (Work Plan Activity 4.2.4). It is anticipated this will increase timely follow-up and referral.

EHDI SOC processes will be sustained after the grant funding cycle ends because practice changes will have been implemented into existing stakeholder's procedures and every day practices.

WORK PLAN

The work plan (Attachment 1) includes the following: Aims, Aim Objectives, Evaluation Measure, Activities/Strategies, Timeline, Responsible Staff, Outputs, and Completion Date. The work plan and GANTT chart (Attachment 6) will serve as tools to guide program planning for the next three years. As described in the methodology section, the QI team will lead the process and utilize quality improvement methodology learned throughout participation in the NICHQ learning collaborative. The QI team will meet every two weeks and adjust the meeting schedule based on progress and need. Below the EHDI program has described proposed small tests of change, partnerships, data analysis and evaluation, and how the successful small tests of change will be spread statewide or re-evaluated.

AIM I: All infants born in Iowa will receive a hearing screen and rescreen (for those that did not pass the birth screen) no later than one month of age.

Aim Objective 1.1: By March 31, 2017, Iowa birthing facilities will decrease the state average number of infants that refer on the birth screen from 6 percent to no more than 4 percent.

Plan: Develop a ranking system for birthing facilities that are meeting or not meeting the EHDI best practices for screening and follow-up.

Do: Identify five birthing facilities not meeting EHDI best practices and have each facility develop a corrective action plan which outlines the steps they are taking to improve best practices.

Study: Review progress of the birthing facilities in meeting EHDI best practices through quarterly birthing facility progress reports (e.g. refer rates, missing PCPs, avg. number of screens, number of days until screen is entered, etc).

Act: If no progress, the program will explore with the birthing facility why the corrective action plan did not lead to progress and work with birthing facility personnel to make necessary changes. For birthing facilities that show improvement, their status on the report will change and they will be congratulated on their progress.

QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI designee from each birthing facility will be added to the QI team to provide input into the design of the PDSA, as well as design of the proposed reports. The QI team will determine how best to "spread" this activity to other facilities in need of improvement.

Aim Objective 1.2: By March 31, 2017, 75 percent of all infants that did not pass their birth screen will have a scheduled outpatient hearing screen appointment no later than one month of age.

Plan: Select five hospitals with the highest number of outpatient screens over the last year that does not have outpatient screens documented in the EHDI database.

Do: Provide training and education to birthing facility personnel on the importance of scheduling outpatient hearing screen appointments prior to discharge and how to document the appointments in the EHDI database.
Study: Review EHDI database report to calculate the percentage of children with an outpatient hearing screen appointment documented in the EHDI database to determine whether the strategy is successful or needs modifications.
Act: Revamp training procedures; continue with the first five birthing facilities and add five more; then spread statewide.
QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI designee from each birthing facility will be added to the QI team to provide input into the design of the PDSA, as well as design of the proposed reports. The QI team will determine how best to "spread" this activity to other facilities in need of improvement.

Aim Objective 1.3: By March 31, 2017, Iowa EHDI will increase by 10 percent the number of infants born out of hospital (i.e. home births, birth centers, etc), that receive a hearing screen.
Plan: Assemble a workgroup that consists of midwives, parents of infants born out of the hospital and EHDI staff to explore attitudes, beliefs and barriers that may impact out of hospital birth screening rates.
Do: Provide educational materials to Iowa midwives and Amish communities regarding hearing loss, timely screening and follow-up.
Study: Review EHDI database report to calculate the percentage of out of hospital births that received a hearing screen and evaluate the LTF/LTD number to determine the effectiveness of recently implemented strategies.
Act: Revise educational materials based on feedback from the workgroup if no progress. If progress, continue to educate midwives and the Amish communities about newborn hearing screening and follow-up.
QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will add the BFH midwife and recruit two other midwives to be a part of the QI team. The QI team will determine how best to "spread" this activity to other midwives and Amish communities.

Aim Objective 1.4: By March 31, 2017, the EHDI program will develop a method of data sharing with other child health reporting systems (e.g. Title V, WIC, and home visiting programs) so the child health programs can assist EHDI personnel in helping families schedule needed hearing follow-up appointments.
Plan: Assemble a workgroup that consists of Title V/WIC/Home visiting program personnel and EHDI staff to develop protocols for follow-up of children in need of a hearing screen or assessment.
Do: Identify and train four Title V/WIC/ Home visiting programs in rural and urban settings to assist families of children in need of a hearing screen or assessment in scheduling appointments.
Study: Review EHDI referral report to calculate the number of families that Title V/Home visiting programs assisted in scheduling hearing screening/assessment appointments. Evaluate the effectiveness (e.g. timeliness, successes and challenges) of the use of WIC/Title V/Home

visiting programs in assisting the EHDI program in getting children in need of hearing screens and audiological assessments to an appropriate provider.
Act: Spread the use of WIC/Title V/Home visiting programs in assisting the EHDI program in getting children in need of hearing screens and audiological assessments to an appropriate provider. If there appears to be no progress, explore reasons, make modifications to the PDSA and test again.
QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will recruit BFH state consultants for each of the programs as well as an individual from the local level (rural and urban) to be a part of the QI team.

AIM II: All infants who do not pass their hearing screen will receive reliable and timely audiological evaluation no later than 3 months of age.

Aim Objective 2.1: By September 30, 2015, Iowa EHDI will increase the percentage of infants from 77 percent to 90 percent that are diagnosed with hearing loss or determined to have normal hearing by no later than 3 months of age.
Plan: Assemble a workgroup (consisting of birthing facility and audiology clinic personnel) and develop a standardized protocol for scheduling a diagnostic assessment following a failed outpatient hearing screen.
Do: Test the implementation of the standardized protocol (which may include template order/referral form) for referral for a diagnostic assessment following a failed outpatient hearing screen in five birthing facilities.
Study: Use the EHDI database report to calculate the percentage of children who received a documented diagnosis of hearing loss or normal hearing by 3 months of age. Evaluate the effectiveness of the standardized protocol to ensure a diagnostic assessment is scheduled within an appropriate timeframe following a failed outpatient hearing screen.
Act: Revamp training procedures; continue with the first five birthing facilities and add five more; then spread statewide.
QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will add the local diagnostic audiology provider and birthing facilities' representation to be a part of the QI team.

Plan: Explore the use of automated/personal phone call to the parents by audiology provider reminding them of the scheduled diagnostic assessment and provide them with necessary instructions for appointment.
Do: Scheduler will provide a telephone reminder the day before the scheduled appointment for five families.
Study: Review the number of families that kept appointments or did not show for the appointments that received a reminder call compared with families that kept appointments or did not show for their appointments that did not receive a reminder call.
Act: Do another PDSA with additional families at a new location.
QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will add diagnostic audiology provider(s) to be a part of the QI team.

Plan: Conduct tele-audiology PDSA with 2 AEAs for 3 months.
Do: Develop protocols and test the use of educational audiologists in two different AEAs to assist the lead EHDI audiologist in performing a diagnostic assessment through tele-audiology.
Study: Speak with the diagnosing lead audiologist and educational audiologists to determine successes and challenges and move forward accordingly.
Act: If successful in the use of AEA educational audiologists to perform diagnostic assessments via tele-audiology, spread this strategy statewide. If not successful, do another PDSA and test a new strategy related to the use of tele-audiology for diagnostic assessments.
QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will add two educational audiologists from the AEAs and the EHDI lead audiologist to this QI team.

AIM III: All infants diagnosed with a permanent hearing loss will be enrolled in early intervention and family support no later than 6 months of age.

Aim Objective 3.1: By March 31, 2017, Iowa EHDI will increase from 50 percent to 75 percent the percentage of infants that are enrolled in early intervention services by six months of age.
Plan: Assemble a workgroup and develop a checklist for audiologists to use when a child has been identified with a hearing loss to ensure all referrals have been made to appropriate providers (e.g. EI, Guide By Your Side (GBYS), ENT, ophthalmology, etc).
Do: Pilot use of the referral checklist in three different audiology clinics.
Study: Use the EHDI database to calculate the percentage of children who were enrolled in EI and family support services by six month of age. Evaluate the effectiveness of the referral checklist and conduct a data comparison between facilities that use the referral checklist against those that do not use the checklist regarding timely and complete referrals.
Act: Share findings with audiology providers and if successful spread the use of the checklist to three additional audiology providers for a final test and then spread the use of checklists statewide.
QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will add a private audiologist to the team.

Aim Objective 3.2: By March 31, 2017, Iowa EHDI will increase the percentage of families enrolled in family support services from 38 percent to 50 percent.
Plan: Assemble a focus group of parents of children with hearing loss and explore methods or outreach ideas to increase the knowledge of parents about the GBYS program.
Do: Develop and distribute a parent survey to all families of children with permanent hearing loss to assess parent knowledge, attitudes and beliefs about newborn hearing screening and follow-up.
Study: Evaluate findings of the 2016 EHDI parent survey including a comparison of the 2011 EHDI parent survey. Evaluate the percentage of children referred and enrolled in the family support services by six months of age.
Act: Share findings with audiology providers and develop a new PDSA to address parental concerns/needs based on the results of the survey.

QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will add two parents of newly diagnosed children with hearing loss to this team.

AIM IV: Families and providers are educated in a way that is culturally and linguistically competent to enhance their understanding and engagement in hearing screening, diagnosis, early intervention and family support.

Aim Objective 4.1: By March 31, 2017, Iowa EHDI will increase the percentage of parent's knowledge of newborn hearing screening and timely follow-up by 15 percent for hospital births and 20 percent for home births.

Plan: Assemble a focus group of prenatal educators (e.g. nurses, childbirth educators) and explore the methods of outreach to increase parent knowledge of newborn hearing screening and follow-up prior to birth.

Do: Educate five prenatal class instructors on newborn hearing screening and the importance of timely follow-up. Prenatal class instructors will further educate new parents in a culturally competent manner about newborn hearing screening and the importance of timely follow-up. Develop and distribute parent survey to a randomized sample of parents of infants born at home and born at a birthing facility to assess parent knowledge, attitudes and beliefs.

Study: Evaluate findings of the 2016 EHDI parent survey including a comparison of the 2011 EHDI parent survey. Use the parent survey results to calculate the increase in knowledge of newborn hearing screen and timely follow-up.

Act: Share findings with stakeholders and develop a new PDSA based on the results of the survey.

QI Team: The EHDI program will work with the QI team described in the methodology section on page 11. Additionally, the EHDI program will include a parent of a newly diagnosed child with hearing loss and a prenatal instructor in this activity.

Aim Objective 4.2: By March 31, 2017, Iowa EHDI will increase the percentage of provider's (Birthing personnel, PCPs, ARNPs, Pediatricians, Family Practice Physicians, OB/GYN, ENTs, and Audiologists) knowledge of best practices related to newborn hearing screening and timely follow-up by 20 percent.

Plan: Conduct a PDSA with two medical schools students (DO/MD).

Do: Iowa EHDI Chapter Champion will train medical students (DO/MD) on hearing screening, importance of timely follow-up, risk factors associated with hearing loss and their role in assisting families in follow-up and assessments.

Study: Use the training survey results to calculate the increase in knowledge of newborn hearing screen and timely follow-up (before training and after training survey).

Act: If successful, spread to the two additional facilities (e.g. nursing colleges). If not successful, revise training materials and do a new PDSA.

QI Team: The EHDI program will work with the QI team described in the methodology section on page 11.

RESOLUTION OF CHALLENGES

The EHDI program has made significant strides in addressing LTF/LTD in the past three years; however, several barriers in building a sustainable system of care remain.

High refer rates

One of the biggest challenges facing the EHDI program includes lowering the state average refer rate to a maximum of 4 percent. Birthing facilities that have a small number of births each year do not gain enough screening experience and therefore, have higher refer rates. The same small birthing facilities also use OAE equipment which tends to have higher refer rates when compared with AABR equipment. Returning to the birthing facility for an outpatient rescreen is a strategy adopted by the EHDI program that has worked well in many communities. The numbers of infants that pass their outpatient hearing screens is approximately 75 percent. By adopting this strategy, the parents do not have to travel long distances for a hearing rescreen because the outpatient rescreen can often be scheduled the day of the child's first well child. The EHDI program is currently evaluating the differences in screening rates for birthing facilities using OAE equipment versus AABR equipment in hopes of encouraging facilities to consider AABR equipment to improve screening outcomes.

Limited Number of Diagnostic Centers in Rural Iowa

Rural areas of the state are served by educational and private audiologists, but often this service has limited hours and the audiologists have less expertise in working with infants. Currently, Iowa has only five diagnostic centers where infants can be evaluated for permanent hearing loss which makes it difficult for rural families to access services in a timely manner. There are also challenges in some instances because the family does not have transportation or the needed financial resources. To overcome this barrier, Iowa EHDI began using tele-audiology technology in a rural community in 2012. An infant was diagnosed with permanent hearing loss in 2013 using this technology. The EHDI program is looking to expand the use of tele-audiology in other rural communities across the state using local AEA audiologists as a resource.

Home Births

Discussions with home birth families and midwives, as well as, a review and analysis of home birth family data and anecdotal data from phone calls with midwives and families revealed a lack of understanding of the importance of hearing screening and midwife attitudes and beliefs about newborn hearing screening to be the main challenges. The EHDI program reached out to the midwife community after recommendations from a midwife that works in the same bureau as EHDI. These efforts were met with resistance unless the program was willing to provide money to support their conference.

To resolve these issues, one strategy the program employed is to partner with a home birth parent whose child was diagnosed with a significant hearing loss to share her personal experience regarding newborn hearing screening with other home birth families. An insert was created for and is distributed in home birth packets; the insert contains her personal story and a picture of mom and baby was included to serve as a reminder to other home birth parents and midwives about the importance of newborn hearing screening. Another strategy used to increase the knowledge regarding hearing screening and resources, is development, an educational toolkit

that was distributed to midwives. The EHDI program received several positive comments about the content of the toolkit following the mailing. The EHDI program also published an article in the monthly Board of Nursing newsletter to highlight best practices for newborn hearing

screening and follow-up. The program intends to reach out to those midwives that provided positive feedback on the toolkit to discuss other ways to increase screening of home birth infants.

Education and Outreach to PCPs

Based on the results of program evaluation activities, including the physician survey (page 12) and follow-up phone calls to PCP offices, some pediatricians and family practice physicians continue to have a "wait-and-see" attitude about newborns who did not pass the hearing screening. This approach has resulted in late identification of infants with hearing loss and it also sends mixed messages to families regarding timeliness of needed follow-up. Strategies in this project include improving the knowledge of PCPs via training and technical assistance. The EHDI program currently uses the Iowa American Academy of Pediatrics (AAP) EHDI Chapter Champion to provide education via phone calls to PCPs that continue to delay referrals for infants and toddlers in need of further testing. The Chapter Champion has scheduled educational training for medical students (MD) at
the University of Iowa and is currently in the process of contacting an additional facility (DO). The training will focus on the importance of newborn hearing screening, risk factors associated with hearing loss and the providers' role in assisting families with timely follow-up and assessments.

Experience and expertise of the EHDI program personnel is described in detail in the Organizational Information section below. The EHDI program will continue to use the expertise of the EHDI audiology technical assistants, as well as the stakeholders on the EHDI advisory committee. The committee stakeholders have been instrumental in influencing their colleagues and assisting the program in decreasing the LTF/LTD rates.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Program evaluation has been ongoing since 2009 with guidance provided by the QI team and EHDI Advisory Committee. A logic model (Attachment 8) was developed by the QI team and has been used to guide program evaluation and future program development. The logic model was created to lay out a visual description of the program's work, link program activities to outcomes, guide decision-making and ensure all EHDI stakeholders understand the vision of the program. The components of the logic model include problem, inputs, activities, outputs, outcomes impact and values.

Data collection for the purposes of analyzing program performance and setting new goals to guide future activities has been gathered primarily through data reports using the statewide web-based EHDI surveillance system, surveys, and focus groups. The EHDI program will have ongoing process and outcome measures to determine the reduction in the rates of LTF/LTD to identify which activities are completed on time, their degree of completeness and data quality. EHDI program personnel will continue to use demographics data to look for trends that may lead to a change in the strategies used for program development and service delivery. For example, through hospital site visits the EHDI coordinator learned that the infants being missed in a particular area of the state were of Amish descent. The EHDI coordinator met with two elders in

two different communities and established a screening program that met their community needs, as well as needs of the program.

At the national level, the state EHDI coordinator (Tammy O'Hollearn) and the follow-up coordinator (Esha Steffen) collaborates with CDC EHDI personnel in the following areas: Iowa EHDI program evaluation and participation on a CDC data committee; development of an interactive online search tool for parents that also will assist state EHDI programs in further analysis of gaps in service areas; the CDC pilot Individual Early Hearing Detection and Intervention (iEHDI) Database project. IDPH EHDI was selected as one of two states to participate in the iEHDI pilot project from 2010-2012. The pilot project was used to determine the feasibility of state EHDI programs providing individual-level data beyond the aggregated data currently provided through the annual CDC screening and follow-up survey. CDC commended IDPH EHDI on their ability to provide high quality individualized data especially in light of the fact there are no dedicated epidemiology staff to assist with the data match between vital records and EHDI database reports, as well as coding.

An article is currently being written on the methodology used to conduct the iEHDI project. This article will be published online in 2014. The CDC and the iEHDI pilot states, including Iowa, will be presenting their initial findings at the 2014 national EHDI conference. In addition, iEHDI pilot states are currently in the process of finalizing an agreement to submit a new 2012 dataset. This data file will compared to the 2010 dataset and will summarize progress in participating states. It will further demonstrate the capability and benefits of EHDI databases providing individualized outcomes data related to the national 1-3-6 goals and highlight state and federal collaboration.

Additional experience and expertise of the EHDI program personnel is described in detail in the Organizational Information section below.

ORGANIZATIONAL INFORMATION

Mission and Structure

Iowa EHDI program's mission is to ensure that all newborns and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, medical intervention and family support.

In 2000, when IDPH received its first CDC cooperative agreement and HRSA grant, several collaborative partners were already working on the state's EHDI infrastructure. These partners included a grassroots advisory committee, the IDPH, EA, AEAs, and birthing facilities and Child Health Specialty Clinics (CHSC). CHSC is Iowa's Title V program for children and youth with special health care needs. All of the same partners participate in EHDI's current SOC. In recent years, the EHDI program has partnered with Title V, Early Head Start, and home visiting programs.

For the last ten years, Iowa's EHDI SOC has been a collaborative effort of two programs, one funded by the CDC (administered by IDPH) and one funded by the HRSA (administered by CHSC). The two programs have worked together to achieve a comprehensive and coordinated

statewide EHDI system. Iowa law designates IDPH as the entity responsible for ensuring there is universal hearing screening in birthing facilities in Iowa. IDPH EHDI resides in the BFH with the CCID, Title V, and other child health programs (Attachment 5). IDPH EHDI is responsible for surveillance, including birth hearing screens and diagnostic assessments of all children under the age of 3 years, data analysis, follow-up (birth through outpatient screen) and program evaluation. The HRSA EHDI program administered by CHSC focused on assuring that all infants and toddlers diagnosed as deaf/HOH receive timely and appropriate follow-up services including diagnosis, medical management and referral to early intervention and family support. CHSC was responsible for risk factor letters and following babies at increased risk of developing late-onset hearing loss. Both programs recognized the interdependency of the multiple phases of the EHDI process and were committed to the development of a seamless system of care.

The Iowa EHDI program also receives funding from EA for the EHDI database, interpreter services, child find and technical assistance. Each of these resources provides a contribution (both funding and expertise) critical to the success of the state's system of care. Finally, the EHDI program had funds appropriated by the Iowa legislature in 2007 through 2014 to cover hearing aid costs not covered by insurance. That funding goes directly to pay for the costs of hearing aids and audiological services (e.g. testing), case management and claims processing.

IDPH will be the lead applicant for HRSA funding in 2014-2017. The partnerships that were in place will remain and CHSC has agreed to work with IDPH to transition the grant smoothly in the first quarter of 2014. At that time, IDPH EHDI will also assume all of the day-to-day responsibilities of follow-up and family support activities previously conducted by CHSC. This will be accomplished through an existing subcontract. The proposed staffing and management plan is included below.

Staffing and Management Plan

Tammy O'Hollearn, LBSW – Ms. O'Hollearn will serve as the program investigator/director (.35 FTE). She will oversee project operations including key personnel, grant activities, coordinate with partner agencies, assure progress in meeting program aim objectives and timely submission of program reports. She will direct data design, collection, program analyses and evaluation of the EHDI SOC. Ms. O'Hollearn has served as the state EHDI coordinator for the last seven and a half years and has been employed with the IDPH since 2001. Prior to 2006, she was involved with early intervention programming, contract management and program development within IDPH. In 2009, she was recognized by the Iowa Speech and Hearing Association (ISHA) for her outstanding service in meeting the needs of Iowa's children who are deaf or hard of hearing and their families.

Esha Steffen, MPH – Ms. Steffen will serve as follow-up coordinator (1.0 FTE). Her primary responsibilities include follow-up with families and PCPs of children that did not pass or missed their hearing screens at birth, children in need of an audiological evaluation and referral to EA and family support. Ms. Steffen will contact families and the infant's PCP to assist in scheduling. She will make referrals to EA if the audiologist or PCP did not make the referral upon diagnosis. Additional responsibilities include quality assurance activities, training, and data analysis and program evaluation. Ms. Steffen has been with the Iowa EHDI program since 2010 and is instrumental in reducing Iowa EHDI's LTF/LTD rate by approximately 20 percent.

Follow-up/Family Support Coordinator (Vacant, .80 FTE) – This individual will be hired upon receipt of grant funds. Job duties will include follow-up of children still in need of a hearing rescreen or assessment by contacting infant's families and PCPs to assist in scheduling. This individual will make referrals to EA if the audiologist or PCP did not make the referral upon diagnosis. In addition, this individual will also oversee the Guide By Your Side (GBYS) program within EHDI which includes contacting parents of newly identified children to enroll in EA and GBYS programs.

Jinifer Cox – This individual will serve as the EHDI program assistant (1.0 FTE, in-kind) Ms. Cox's responsibilities include performing data entry, conducting quality assurance checks in the EHDI database, completing a weekly data match between the EHDI database and vital records data, serving as a technical assistant for data entry questions, and token manager for the EHDI program. Ms. Cox has worked with EHDI for eight years and demonstrates a high level of detail in her work.

Shannon Sullivan, MD – Dr. Sullivan serves as Iowa AAP EHDI Chapter Champion (In-kind). She will train medical students (DO/MD) on hearing screening, importance of timely follow-up, risk factors associated with hearing loss and their role in assisting families with follow-up and assessments (Work Plan Activity 4.2.4). Dr. Sullivan has served in this capacity since April 2011. She is a member of the QI team and EHDI Advisory Committee. Over the last two years she has presented with the EHDI coordinator at Grand Rounds at our largest birthing facilities.

See Attachment 2 for job descriptions, Attachment 3 for biographical sketches and Attachment 5 for Iowa EHDI's organizational chart.

The capacity of Iowa's EHDI program is evident not only through the progress made on screening, surveillance, intervention and reporting, but also through increased community awareness and the public commitment it has garnered as evidenced with increased reporting. Additionally, responses to the EHDI newsletter, website and weekly email communication suggest that the community is undoubtedly more aware of and interested in early hearing detection and intervention in Iowa.

Capabilities to Provide Culturally Competent Services

The EHDI program hired a bilingual follow-up coordinator in 2010. This individual speaks Hindi (national language of India). This has helped the program reach families that could have been lost due to language barriers in the past.

To assist Spanish speaking families whose children are in need of a hearing screen or rescreen, the state EHDI coordinator worked with EA Iowa to create a system of follow-up using their bilingual referral specialists. EA Iowa is currently the referral source for EA and EHDI. Their bilingual referral specialists are available each day until 7 p.m. The follow-up coordinator creates and sends a referral sheet on a monthly basis to EA Iowa for each Spanish speaking family whose child needs a hearing screen/rescreen. Prior to the referral, she has contacted the child's PCP to communicate needed follow-up. Upon receipt of the referral, EA Iowa then calls the family and assists them with scheduling an appointment directly with a local service provider

who does outpatient hearing screens, typically the AEAs. They report back to the follow-up coordinator the outcome of the phone call with the family, including the date and time of the appointment or the inability to reach the family. The system has worked well over the last two years and data shows the number of Spanish speaking families receiving needed follow-up has improved.

The EHDI coordinator initiated a conversation with two Amish communities in 2009 following several hospital site visits. Nurses at the hospital indicated that many Amish families would leave the hospital shortly after the infant's birth and never receive a hearing screen. Both Amish communities expressed a willingness to have an audiologist come into their communities to screen infants and toddlers for hearing loss. One elder opened his home as the location for the screenings to take place while the other location uses their community center. This has helped to reduce the number of infants missed in those communities. Additional efforts have been made to reach out to other Amish elders to explore setting up similar screening programs, however, in that Amish community the elder said he would need to take the information to the Bishop for consideration. The EHDI program has not heard from the elder, but has plans in the future to partner with the newborn dried bloodspot screening program to reach out to that community and another community to set up a local screening program (Work Plan Activity 1.3.4).

Iowa EHDI has expanded their EHDI Advisory Committee and added an additional deaf adult, a parent of a child with a cochlear implant, as well as a parent of a child that uses American Sign Language as their first language. Their input has been invaluable in developing culturally diverse materials. These individuals most recently assisted the EHDI program in revising the EHDI Family Resource Guide and provided input into the design and organization of the EHDI website that will be completed in 2014.

Lastly, the EHDI program has participated with four other states and the territory of Guam in a Community of Learners (COL) to improve cultural and linguistic competence in the EHDI SOC. The COL is sponsored by NCHAM at Utah State University and the National Center for Cultural Competence at Georgetown University. The goal was to have a clearly defined congruent set of values and principles and demonstrate behaviors, attitudes, policies, structures, and practices that enable each member of the EHDI staff to work effectively cross-culturally. The Iowa EHDI program is dedicated to advocate for cultural and linguistic competence in system improvement efforts.

Attachment 1 – 2014 - 2017 Work Plan
Reducing Lost to Follow-up After Failure to Pass Newborn Hearing Screening - Iowa

Healthy People 2020: Increase the proportion of newborns who are screened for hearing loss by no later than age 1 month.

AIM I: All infants born in Iowa will receive a hearing screen and rescreen (for those that did not pass) no later than one month of age.

Aim Objective 1.1: By March 31, 2017, Iowa birthing facilities will decrease the state average number of infants that refer on the birth screen from 6 percent to no more than 4 percent.
Evaluation: Compare the refer rate analysis for each birthing facility from the EHDI database on a quarterly basis.

ACTIVITIES/STRATEGIES	TIMELINE	RESPONSIBLE STAFF	OUTPUTS
Activity 1.1.1 Develop a ranking system for birthing facilities which highlights facilities that are meeting/not meeting JCIH recommended EHDI best practices for screening and follow-up.	April 1, 2014 – September 30, 2014	EC FUC BFP	A birthing facility report card will be available.
Activity 1.1.2 EHDI staff will assist four birthing facilities in the development of a corrective action plan to improve compliance in meeting state and national EHDI goals.	Quarterly	EC FUC	Action plan will be developed and exchanged through email.
Activity 1.1.3 EHDI staff will review progress of birthing facilities in meeting EHDI best practices and provide feedback based on the results.	Quarterly	EC FUC PDSA Team	Quarterly reports will be completed and sent to birthing facilities; Iowa EHDI Birthing Facility Report Card.

Aim Objective 1.2: By March 31, 2017, 75 percent of all infants that did not pass their birth screen will have a scheduled outpatient hearing screen appointment no later than one month of age.
Evaluation: Review EHDI database report to calculate the percentage of children with an outpatient hearing screen appointment documented in the EHDI database.

ACTIVITIES/STRATEGIES	TIMELINE	RESPONSIBLE STAFF	OUTPUTS
Activity 1.2.1 Provide training and educate birthing facility personnel on standardized reporting of scheduled outpatient hearing screen appointments.	Semi-annually	FUC	Evidence of webinar or email exchange between EHDI personnel and birth facility contact available.

Responsible Staff Acronym Key

BFP – Birthing Facility Personnel
EC – EHDI Coordinator, Tammy O'Hollearn
EHDI ACM- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant
FUC- Follow up Coordinator, Esha Steffen
LA – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)

Activity 1.2.2 FU Coordinator will continue to assist families in locating an outpatient screening provider in the community for out of hospital births and for hospitals births that were not screened prior to discharge.	Bi-monthly	FUC FSC	Evidence of assistance will be documented in the case management section of the child's medical record.
Activity 1.2.3 Educate PCPs on the importance of assisting families at the time of the well child visits in scheduling necessary hearing screen appointments for infants.	Bi-monthly	FUC FSC	Evidence of assistance will be documented in the case management section of the child's medical record; Educational materials developed and distributed to providers via letter/newsletter article.
Aim Objective 1.3: By March 31, 2017, Iowa EHDI will increase the number of infants born out of hospital (i.e. home births, birth centers, etc.), that receive a hearing screen by 10 percent. **Evaluation:** Review EHDI database report to calculate the percentage of out of hospital births that received a hearing screen.			
ACTIVITIES/STRATEGIES	**TIMELINE**	**RESPONSIBLE STAFF**	**OUTPUTS**
Activity 1.3.1 Assemble a workgroup that consists of midwives, parents of infants born out of the hospital and EHDI staff to explore attitudes, beliefs and barriers that may impact out of hospital birth screening rates.	January – July 31, 2015	EC FUC	Email/postcard/letter available documenting invitation to workgroup meeting.
Activity 1.3.2 Out of hospital birth workgroup will review and revise educational materials for out of hospital birth families.	August 2015 – March 31, 2016	EC FUC	Meeting minutes will include documentation of recommendations/revisions of educational materials.
Activity 1.3.3 Provide educational materials to Iowa midwives regarding hearing loss, timely screening and follow-up.	Semi-annually	EC FUC FSC	Educational materials developed and distributed to midwives via letter/newsletter/conference.
Activity 1.3.4 Explore expansion of a hearing screening program for the Amish community in NE/Southern part of the state.	January 2015 – December 2016	EC FUC	Evidence of email exchange between EHDI and bloodspot screening personnel/letter to Amish elder available; Meeting minutes available, if applicable.

Responsible Staff Acronym Key		
BFP – Birthing Facility Personnel	**EC** – EHDI Coordinator, Tammy O'Hollearn	**EHDI ACM**- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant	**FUC**- Follow up Coordinator, Esha Steffen	**LA** – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)		

Activity 1.3.5 Evaluate out of hospital birth screening rates and lost to follow-up numbers to determine the effectiveness of recently implemented initiatives.	Annually	EC FUC	Comparison of before and after screening report for out of hospital births.
Aim Objective 1.4: By March 31, 2017, the EHDI program will develop a method of data sharing with other child health reporting systems (e.g. Title V, WIC, home visiting programs) so the child health programs can assist EHDI personnel in helping families schedule needed hearing follow- up appointments. **Evaluation:** Review EHDI referral report to calculate the number of families that Title V/WIC/Home visiting programs assisted in scheduling hearing screening/assessment appointments.			
ACTIVITIES/STRATEGIES	**TIMELINE**	**RESPONSIBLE STAFF**	**OUTPUTS**
Activity 1.4.1 Assemble a workgroup that consists of Title V/WIC/Home visiting program personnel and EHDI staff to develop protocols for follow-up of children in need of a hearing screen or assessment.	January – March 31, 2015	EC FUC FSC	Evidence of email exchange between EHDI and Title V/WIC/Home visiting program personnel for invitation to workgroup; A copy of the protocol will be available.
Activity 1.4.2 Identify and train four Title V/WIC/Home visiting programs in rural and urban settings to assist families of children in need of a hearing screen or assessment in finding the appropriate resources.	April 2015 – March 31, 2016	EC FUC FSC	Evidence of training available (e.g. sign in sheet/list of participants)
Activity 1.4.3 Evaluate the effectiveness of the use of Title V/WIC/Home visiting programs in assisting the EHDI program in getting children in need of hearing screens and audiological assessments to an appropriate provider.	April 2016 – March 31, 2017	EC FUC PDSA Team	Comparison of before and after diagnostic and compliance report (which includes OP screen, appointment date and date of entry); Evidence of email exchange between EHDI and designated hospital/ audiology provider that outlines successes and challenges (e.g. not enough diagnostic audiology appt. slots available).
Activity 1.4.4 Spread the use of Title V/WIC/Home visiting programs in assisting the EHDI program in getting children in need of hearing screens and audiological assessments to an appropriate provider.	July 2015 March 31, 2017	EC FUC	Evidence of training available (e.g. sign in sheet/list of participants).

Responsible Staff Acronym Key		
BFP – Birthing Facility Personnel	**EC** – EHDI Coordinator, Tammy O'Hollearn	**EHDI ACM**- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant	**FUC**- Follow up Coordinator, Esha Steffen	**LA** – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)		

Healthy People 2020: Increase the proportion of newborns who receive audiologic evaluation no later than 3 months for infants who did not pass the hearing screening.			
AIM II: All infants who do not pass their hearing screen will receive reliable and timely audiological evaluation no later than 3 months of age.			
Aim Objective 2.1: By September 30, 2015, Iowa EHDI will increase the percentage of infants from 77 percent to 90 percent that are diagnosed or determined to have normal hearing no later than 3 months of age. **Evaluation:** Use the EHDI database report to calculate the percentage of children who received a documented diagnosis of hearing loss or normal hearing by 3 months of age.			
ACTIVITIES/STRATEGIES	**TIMELINE**	**RESPONSIBLE STAFF**	**OUTPUTS**
Activity 2.1.1 Assemble workgroups (consisting of hospital and audiology clinic personnel) and develop a standardized protocol for scheduling a diagnostic assessment following a failed outpatient hearing screen.	October – December 31, 2016.	EC FUC FSC	Evidence of email exchange between EHDI and advisory committee member audiologists for invitation to workgroup; Standardized protocol developed and included in the Iowa EHDI Best Practices Manual related to diagnostic assessment scheduled upon failed outpatient hearing screen.
Activity 2.1.2 Work with a hospital and audiology provider to test the implementation of the standardized protocol (which may include template order/referral form) for referral for a diagnostic assessment following a failed outpatient hearing screen.	January – June 30, 2015	EC FUC PDSA Team	Evidence of email exchange between EHDI and designated hospital/audiology provider that outlines successes and challenges.
Activity 2.1.3 Explore the use of automated/personal phone call to the parents by audiology provider reminding them of the scheduled diagnostic assessment and provide them with necessary instructions for appointment.	October 2014 – June 30, 2015	EC FUC PDSA Team	Evidence of email exchange between EHDI and audiology provider that outlines agreement and if agreement, their plan for implementation.
Activity 2.1.4 Evaluate the effectiveness of the standardized protocol to ensure a diagnostic assessment is scheduled within a timely manner following a failed outpatient hearing screen.	July – September 30, 2015	EC FUC PDSA Team	Comparison of before and after diagnostic and compliance report (which includes OP screen, appointment date and date of entry); Evidence of email exchange between EHDI and designated hospital/ audiology provider that outlines successes and challenges (e.g. not enough diagnostic audiology appt. slots available).

Responsible Staff Acronym Key		
BFP – Birthing Facility Personnel	**EC** – EHDI Coordinator, Tammy O'Hollearn	**EHDI ACM**- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant	**FUC**- Follow up Coordinator, Esha Steffen	**LA** – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)		

Activity 2.1.5 Explore the use of Area Education Agency audiologists to assist in the use of tele-audiology across the state to complete diagnostic assessment in a timely manner.	July - December 31, 2014	LA	Evidence of phone/email exchange between EHDI Lead Audiologist and AEA audiology personnel.
Activity 2.1.6 Develop protocols for tele-audiology, including roles and responsibilities, equipment use, etc.	January – June 30, 2015	LA	Protocols included in Iowa EHDI Best Practices Manual on Iowa EHDI website, http://www.idph.state.ia.us/iaehdi
Healthy People 2020: Increase the proportion of infants with confirmed hearing loss who are enrolled in early intervention services no later than 6 months of age.			
AIM III: All infants diagnosed with a permanent hearing loss will be enrolled in early intervention and family support no later than 6 months of age.			
Aim Objective 3.1: By March 31, 2017, Iowa EHDI will increase the percentage of infants from 50 percent to 75 percent that are enrolled in early intervention services by six months of age. **Evaluation:** Use the EHDI database to calculate the percentage of children who were enrolled in the early intervention and family support services by six months of age.			
ACTIVITIES/STRATEGIES	**TIMELINE**	**RESPONSIBLE STAFF**	**OUTPUTS**
Activity 3.1.1 Assemble a workgroup and develop a checklist for audiologists to use when a child has been identified with a hearing loss to ensure all referrals have been made to appropriate providers (e.g. EI, GBYS, ENT, ophthalmology, etc.).	July - September 30, 2015	EC FUC PDSA Team	Evidence of email exchange between EHDI and advisory committee member audiologists for invitation to workgroup; A copy of the referral checklist will be available on the EHDI website.
Activity 3.1.2 Pilot use of the referral checklist in three different audiology clinics.	September 2015 – June 30, 2015	Audiology Clinics	Evidence of email exchange, conference call outlining instructions for the pilot audiology clinics.
Activity 3.1.3 Evaluate the effectiveness of the referral checklist and conduct a data comparison between facilities that use the referral checklist against those that do not use the checklist regarding timely and complete referrals.	April – September 30, 2016	EC FUC PDSA Team	Evidence of email exchange between EHDI and designated hospital/audiology provider that outlines successes and challenges of implementing a referral checklist; Comparison of referral dates to EA/GBYS for pilot facilities using the checklist vs. those that do not use the checklist utilizing the EHDI diagnostic/case management reports.

Responsible Staff Acronym Key		
BFP – Birthing Facility Personnel	**EC** – EHDI Coordinator, Tammy O'Hollearn	**EHDI ACM**- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant	**FUC**- Follow up Coordinator, Esha Steffen	**LA** – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)		

Activity 3.1.4 Share findings with audiology providers and explore the possibility of spreading the use of checklists statewide.	October 2016 – March 31, 2017	EC FUC	Evidence of email or newsletter article.
Aim Objective 3.2: By March 31, 2017, Iowa EHDI will increase the percentage of families enrolled in family support services from 38 percent to 50 percent. **Evaluation:** Use the EHDI database to calculate the percentage of children referred and enrolled in the family support services by six months of age.			
ACTIVITIES/STRATEGIES	**TIMELINE**	**RESPONSIBLE STAFF**	**OUTPUTS**
Activity 3.2.1 Educate audiology providers on the GBYS program and referral process.	October 2014 – March 31, 2017	FSC	Evidence of email, newsletter article or meeting minutes.
Activity 3.2.2 Increase participation of families of newly diagnosed children with hearing loss in the EHDI program (e.g. additional EHDI advisory committee members, work groups, articles in the EHDI or provider newsletters and monthly parent calls).	January 2015 -- March 31, 2017	FSC	Evidence of email, newsletter article, EHDI advisory committee minutes or EHDI membership list.
Activity 3.2.3 Assemble a focus group of parents of children with hearing loss and explore methods or outreach ideas to increase the knowledge of parents about the GBYS program.	January – December 31, 2015	EC FUC FSC PDSA Team	Evidence of email exchange between EHDI and parent support for invitation to workgroup.
Activity 3.2.4 Develop and distribute a parent survey to all families of children with permanent hearing loss to assess parent knowledge, attitudes and beliefs about newborn hearing screening and follow-up.	July – September 30, 2016	EC FUC FSC PDSA Team	Parent survey available.
Activity 3.2.5 Evaluate and share findings of the 2016 EHDI parent survey including a comparison of the 2011 EHDI parent survey.	October 1, 2014 – March 31, 2017	EC FUC FSC	A copy of the EHDI parent survey results will be available and published in the EHDI newsletter and presented at the EHDI advisory committee meeting.

Responsible Staff Acronym Key		
BFP – Birthing Facility Personnel	**EC** – EHDI Coordinator, Tammy O'Hollearn	**EHDI ACM**- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant	**FUC**- Follow up Coordinator, Esha Steffen	**LA** – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)		

Healthy People 2020: Increase the proportion of infants with confirmed hearing loss who are enrolled in early intervention services no later than 6 months of age.			
AIM IV: Families and providers are educated in a way that is culturally and linguistically competent to enhance their understanding and engagement in hearing screening, diagnosis and intervention.			
Aim Objective 4.1: By March 31, 2017, Iowa EHDI will increase the percentage of parent's knowledge of newborn hearing screening and timely follow-up by 15 percent for hospital births and 20 percent for home births. **Evaluation:** Use the parent survey results to calculate the increase in knowledge of newborn hearing screen and timely follow-up.			
ACTIVITIES/STRATEGIES	**TIMELINE**	**RESPONSIBLE STAFF**	**OUTPUTS**
Activity 4.1.1 Review, update and disseminate current parent roadmap to providers.	April 2014 – March 31, 2015	FSC	Evidence of new parent roadmap will be included on the Iowa EHDI website, http://www.idph.state.ia.us/iaehdi
Activity 4.1.2 Assemble a focus group of prenatal educators (e.g. nurses) and explore the methods of outreach to increase parent knowledge of newborn hearing screening and follow-up prior to birth.	January – March 31, 2015	FUC FSC PDSA Team	Evidence of email exchange between EHDI and prenatal educators for invitation to workgroup.
Activity 4.1.3 Educate prenatal class instructors on newborn hearing screening and the importance of timely follow-up.	April – June 30, 2015	FUC FSC	`Evidence of webinar or training available (e.g. sign in sheet/list of participants)
Activity 4.1.4 Prenatal class instructors will educate new parents in a culturally competent manner via class, online training, brochures, etc. about newborn hearing screening and the importance of timely follow-up.	July 1, 2015 -- March 31, 2016	FUC FSC	Evidence of webinar or training available (e.g. sign in sheet/list of participants) and educational materials used.
Activity 4.1.5 Develop and distribute a parent survey to a randomized sample of parents of infants born at home and the hospital to assess parental knowledge, attitudes and beliefs.	July 1, 2015 -- September 30, 2016	EC FUC FSC PDSA Team	Parent survey available.
Activity 4.1.6 Evaluate and share findings of the 2016 EHDI parent survey including a comparison of the 2011 EHDI parent survey.	October 1, 2016 – March 31, 2017	EC FUC FSC PDSA Team	A copy of the EHDI parent survey results will be available and published in the EHDI newsletter and presented at the EHDI advisory committee meeting.

Responsible Staff Acronym Key		
BFP – Birthing Facility Personnel	**EC** – EHDI Coordinator, Tammy O'Hollearn	**EHDI ACM**- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant	**FUC**- Follow up Coordinator, Esha Steffen	**LA** – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)		

Aim Objective 4.2: By March 31, 2017, Iowa EHDI will increase the percentage of provider's (Birthing personnel, PCPs, ARNPs, Pediatricians, Family Practice Physicians, OB/GYN, ENTs, and Audiologists) knowledge of best practices related to newborn hearing screening and timely follow-up by 20%. **Evaluation:** Use the provider survey or training survey results to calculate the increase in knowledge of newborn hearing screen and timely follow- up.			
ACTIVITIES/STRATEGIES	**TIMELINE**	**RESPONSIBLE STAFF**	**OUTPUTS**
Activity 4.2.1 Educate birthing facility personnel and audiologists / ENTs on newborn hearing screening and assessment best practices (1-3-6).	Weekly	EC FUC FSC	Evidence of webinar or training available (e.g. sign in sheet/list of participants); A copy of the training feedback form/knowledge questionnaire will be available; EHDI Tip of the Week made available through the email/EHDI website.
Activity 4.2.2 Educate EHDI staff, birthing facility personnel and audiologists on the impact of cultural differences on EHDI LTF/LTD numbers.	Biennial – September 2014, 2016	EC FUC FSC	Iowa EHDI Symposium Agenda; A copy of the training feedback form/knowledge questionnaire will be available.
Activity 4.2.3 Educate and provide resource materials to PCPs and OB/GYNs regarding newborn hearing screening and timely referral and follow up.	Semi-annually	EC FUC FSC	Evidence will be provided in the form of a newsletter article, email, conference presentation and training.
Activity 4.2.4 Iowa EHDI Chapter Champion will train medical students (DO/MD) on hearing screening, importance of timely follow-up, risk factors associated with HL and their role in assisting families in follow up and assessments.	Annually	EHDI Chapter Champion	Evidence of training available (e.g. sign in sheet/list of participants) A copy of the training feedback form/knowledge questionnaire will be available.
Activity 4.2.5 Assemble a workgroup (including birthing facility staff, audiologists, EHDI staff, parents, etc.) to review and update the current Iowa EHDI Best Practices Manual.	April 2014 – March 31, 2015	EC FUC FSC Iowa EHDI ACM	Second edition of Iowa EHDI Best Practices Manual will be posted to the Iowa EHDI website.
Activity 4.2.6 Review and update the current EHDI website and screening brochure.	April 2014 – March 31, 2015	EC FUC FSC	Evidence of new EHDI website and modified screening brochure are available at, http://www.idph.state.ia.us/iaehdi
Activity 4.2.7 Evaluate and share findings of the educational opportunities with PDSA team to determine if the education efforts should continue, increase in frequency or end.	Annually	EC FUC FSC PDSA Team	Findings available in meeting minutes of PDSA team meeting and/or Iowa EHDI Advisory Committee Meeting.

Responsible Staff Acronym Key		
BFP – Birthing Facility Personnel	**EC** – EHDI Coordinator, Tammy O'Hollearn	**EHDI ACM**- EHDI Advisory Committee Members
FSC-Family Support Coordinator, Vacant	**FUC**- Follow up Coordinator, Esha Steffen	**LA** – Lead Audiologist, Emily Andrews
PDSA Team – QI team (members will change depending on strategies)		