IOWA EHDI PERFORMANCE NARRATIVE

PROJECT IDENTIFIER INFORMATION

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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 received timely and appropriate services and family support. The time between screening to diagnosis and age when early intervention (EI) and family support is provided continues to improve. 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 accomplishments, barriers, progress with goals and objectives, changes in personnel or project goals and objectives, and plans for the upcoming budget year.

ACCOMPLISHMENTS AND BARRIERS

ACCOMPLISHMENTS

In April 2014, the EHDI team met and explored the National Institute for Children's Health Quality (NICHQ) driver diagram to explore the strategies previously identified in the fall of 2013. The team met to ensure the strategies that were identified would build upon program successes and address areas of need within the EHDI System of Care (SOC). Prioritization of the strategies was based upon available resources (e.g. financial means, time, and personnel) and perceived ability to make the biggest impact on decreasing the numbers of infants Lost to Follow-up/Lost to Documentation (LTF/LTD) and improving timely referral and enrollment in EI services.

One accomplishment the EHDI program is proud of is the program was selected to present at the annual Iowa Academy of Family Physicians (IAFP) conference on November 14, 2014. This is significant because the program reached out to the academy for a number of years to provide

education and outreach and has never been selected to present. In the last two years, the family physician representative that serves on the EHDI Advisory Committee has been a strong advocate for the program and it paid off. The state EHDI coordinator, Iowa EHDI American Academy of Pediatrics (AAP) Chapter Champion and EHDI lead audiologist presented at the annual conference and received high marks.

The EHDI coordinator, EHDI lead audiologist and an audiology intern presented a poster on October 24, 2014 at the annual Iowa Speech-Language Hearing Association (ISHA) conference on LTF/LTD and analysis the program completed on demographics of children diagnosed with a hearing loss, including risk factors most often associated with congenital and late onset hearing loss. Additionally, the Iowa EHDI AAP Chapter Champion was successful in getting EHDI included in the University of Iowa residency program content and it will be covered during their rotation in pediatrics and family medicine. Next semester the nurse practitioner program will also include a presentation on EHDI. Hearing about the importance of newborn hearing screening, timely follow-up and risk factor monitoring during physician and nurse practitioner training will bring emphasis to its importance and reinforce the role they might one day play in timely follow-up.

Another accomplishment in this reporting period was finalizing a parent road map to be used when an infant does not pass their hearing screen at birth. The map outlines next steps through the point of diagnosis and referral to EI and family support programs. The EHDI advisory committee worked to develop this map a couple of years ago but was not able to finish the map because of wording and agreement on its content. The EHDI program is finalizing the appearance of the new map and it will be piloted in several hospitals to explore implementation state-wide in the upcoming months.

Even in the absence of a Follow-up/Family Support program coordinator, the EHDI program was able to accomplish the following:

- Complete evaluation and analysis of LTF/LTD data and referral rates of hospitals using Otoacoustic Emissions (OAE) versus Automatic Auditory Brainstem Response (AABR) screening
- Prepare quarterly quality assurance progress reports for 79 birthing facilities
- Make 3,437 contacts for infants in need of further testing
- Prepare presentations for the IAFP and ISHA conferences and two upcoming webinar trainings for birthing facilities
- Finalize a parent road map for parents of infants that did not pass their birth screen

BARRIERS

The most significant barrier was the delay in hiring a Follow-up/Family Support Coordinator, .75 FTE. The program could not submit the paperwork to hire until the notice of grant award (NOA) was received. The NOA was received April 26. The position was not approved and posted until August 2014. There were approximately 70 applicants for this position. To help narrow the interview pool, the EHDI program sent a survey. The program received approximately 50 surveys back. Resumes and surveys were scored and interviews took place in October. An offer was made at the end of October and the new employee was not able to begin employment until

November 17. The shortage in personnel affected the program's ability to follow-up on children in need of a diagnostic assessment and in ensuring children identified with a hearing loss were referred to EI and family support. The full time EHDI program staff already has more work than personnel so the team had to re-prioritize activities. Additionally, the absence of a Follow-up/Family Support Coordinator for months has threatened the status of Iowa's Guide By Your Side program recognition nationally.

AIM (GOALS) AND AIM OBJECTIVE PROGRESS

The following is an update on activities used to meet specific aims and objectives.

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.

Activities under this aim and objective are focused on technical assistance to the birthing facilities not meeting best practices. Technical assistance was provided to multiple birthing facilities in the first three quarters following receipt of this grant; however, only four facilities were selected to assist in the development of a corrective action plan. Two facilities were selected because their refer rates averaged more than 15 percent since January 2014. Both facilities were offered training by an EHDI audiologist or they could choose to have their staff complete the online National Center for Hearing Assessment and Management screening curriculum. One facility was trained by an EHDI audiologist and the other had their staff utilize the online training. Both facilities decreased their refer rates significantly; one went from 18 percent to eight (8) percent and the other facility went from 15 to 10 percent.Additionally, EHDI staff sent an email to all birthing facilities contacts about refer rates being above state and national refer rate recommendations. Since that time the state average decreased from six percent to five.

Two additional facilities were selected to complete corrective action plans because of data entry error issues. The incorrect results led to unnecessary follow-up by EHDI personnel with families and the infant's primary care provider. In other instances the infant did not receive a timely re-screen because they thought their infant had passed their hearing screen at birth when the infant had not. In both of these instances, the EHDI coordinator worked with the nurse manager. One facility was importing demographics but not the screening results from their equipment. Instructions were provided to the birthing facility to set up the import of screen results from the hearing screening equipment to the database to remove the opportunity for human data entry errors. The EHDI coordinator also suggested they have another staff person complete quality assurance checks on the entry until the screen results import could be set up. At the second facility, the Iowa EHDI coordinator met with hospital information technology staff to review the import process for demographics as well as results from hearing screening equipment. The goal is have the import file developed and tested by the Iowa EHDI database vendor by January 1, 2015.

Currently, the EHDI program provides a quarterly progress report for each birthing facility that includes progress on variables associated with state law and recommended best practices. EHDI personnel took examples of three state report cards to the EHDI Advisory Committee meeting in

April 2014 and developed a ranking system at the meeting in July 2014. The report cards are similar to the quarterly progress reports, but also include a ranking component giving hospitals the opportunity to see where they are in comparison with other birth facilities of the same size. In the next quarter, the report will be piloted and finalized.

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

EHDI personnel provide bimonthly tips to all birthing facility EHDI contacts reviewing recommended best practices. The importance of scheduling outpatient hearing screens prior to hospital discharge is one of the many topics covered in the bimonthly tips. In December, there are two webinar trainings for hospital EHDI contacts. This topic will also be covered at that time.

The EHDI follow-up coordinator continues to contact all parents and primary care providers of infants in need of a hearing screen/re-screen or diagnostic assessment. Preliminary data for the first ten months of 2014 shows Iowa EHDI personnel have made a total of 3,437 contacts. The largest number of contacts made was 1,960 by phone with email coming in second at 1,297. Contacts by email are most likely to birthing facilities, outpatient screening clinics or audiologists. Contacts by phone are made to parents and the infant's primary care provider. A few contacts have been made more recently to parents by SMS text (25). The majority of contacts were made by the EHDI follow-up coordinator at 2,385.

The third activity under this aim objective was targeted at education of primary care providers. As noted in the accomplishment section of this report, the state EHDI coordinator, EHDI lead audiologist and AAP Chapter Champion for Iowa presented EHDI LTF/LTD data and reinforced the medical home's responsibility at the IAFP conference on November 14, 2014.

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.

During this reporting period, the only activity to report is the plan to provide educational materials to Iowa midwives regarding hearing loss, timely screening and follow-up. EHDI personnel developed educational materials to send to nurse midwives in January 2015. In the correspondence, there will be a comparison between out of hospital and home births. The data summarized will include the number of infants screened, LTF/LTD and refusals. There will also be a letter from a parent whose child was born at home that was screened and diagnosed with a hearing loss and the impact timely screening had on their family.

Aim Objective 1.4: By March 31, 2017, 75 percent of all infants that did not pass their birth screen will have an outpatient hearing screen appointment no later than one month of age.

All activities under Aim Objective 1.4 begin in 2015 or 2016.

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.

Only activity 2.1.5 began in this reporting period. In October 2014 at the quarterly EHDI Advisory Committee meeting, the EHDI coordinator explored the use of Area Education Agency (AEA) audiologists to assist in the use of tele-audiology across the state. The goal of this activity is to increase timely diagnostic hearing assessments and decrease driving time for families of infants that do not pass the outpatient hearing screen. The proposal was well received at the meeting and the Iowa School for the Deaf (ISD) offered to pay for a second piece of diagnostic hearing equipment if the initial pilot is successful. An audiologist from the AEA agreed to send out an email to other AEA audiologists to explore their interest and gather their questions, comments and concerns. A follow-up meeting was held via webinar on November 17 with two audiologists from the AEAs, two state EHDI program audiologists, ISD administrator, early interventionist from an AEA and state EHDI coordinator in attendance. The goal of the meeting was to address AEA audiologists' concerns, explore which AEAs were interested in serving as pilot programs and come up with a preliminary plan. Two AEAs expressed an interest in participating in the pilot. The EHDI coordinator and lead EHDI audiologist are putting together a plan for training and mentorship. The committee also determined the pilot would not begin until the spring of 2015 due to the upcoming holidays, vacations and weather that may affect travel time for training.

AIM III: All infants diagnosed with a permanent hearing loss will be enrolled in early intervention services 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 and family support services by six months of age.
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.

All activities under Aim Objective 3.1 and 3.2 are scheduled to begin at the end of 2014 or in 2015. It might be necessary to extend the timeline for two activities under these objectives due to the delay in hiring a Follow-up/Family Support Coordinator.

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.

As noted under accomplishments, the EHDI program was able to finalize the parent road map. The map will be piloted after the first of the year with several hospitals to evaluate its use by hospitals and parents and ensure no revisions are needed to the map prior to statewide dissemination. All other activities under Aim Objective 4.1 do not begin until 2015.

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%,

All EHDI personnel educate birthing facilities, audiologists, PCPs and ENTs on best practices weekly through phone calls and email. As noted above, the EHDI program presented to audiologists in attendance at the ISHA conference in October and family physicians at their annual conference in November 2014. Additionally, the EHDI coordinator presented to the Early Head Start programs at their quarterly meeting in November 2014.

Four audiology clinics were trained during this reporting period by one of the EHDI pediatric audiology technical assistants. Training included a review of best practices, as well as "hands on" training on the entry of hearing screens and diagnostic assessment results into the EHDI database. All birthing facility contacts for EHDI were notified and strongly encouraged to attend one of two webinars being offered in December. The webinar will cover program progress to date including statistics, outcomes for children and compliance with recommended best practices and EHDI law/rules.

As noted under accomplishments, the Iowa EHDI AAP Chapter Champion was successful in getting EHDI included in the University of Iowa residency program content and it will be covered during their rotation in pediatrics and family medicine. The nurse practitioner program will also include a presentation on EHDI during the next semester.

In April 2014, the EHDI advisory committee reviewed the best practices manual to make initial suggestions on content changes and/or revisions. The EHDI audiology technical assistants met during the summer months to update audiology protocols and recommended best practices related to screening and diagnosis. Final revisions will be made over the next six months with the goal of distribution in the summer of 2015.

SIGNIFICANT CHANGES

When the IDPH program took over administration of the HRSA EHDI grant, including additional follow-up and family support, it meant a person needed to be hired to assist current personnel in completing the work. After delays in hiring, Shalome Lynch was hired as the the new .75 FTE Follow-up/Family Support Coordinator. She began work on November 17. Shalome is bilingual. Spanish is her first language and English is her second. She has her Bachelor's degree in Sociology and Child and Family Services. Her experience includes care coordination, home visitation, parent education and connecting families to EI services. Having an additional person available to assist with follow-up, family support referrals and analysis will greatly benefit the EHDI program. There are no other changes to report regarding personnel, project aims, aim objectives or timeframes at this time.

PLANS FOR UPCOMING BUDGET

The EHDI program has plans to pilot the birth facility ranking system now that there is another follow-up coordinator hired who can assist with weekly follow-up calls and emails to families and primary care providers. The ranking system will highlight which birthing facilities are

meeting best practices for screening and follow-up recommended by the Joint Committee on Infant Hearing. During the pilot, the EHDI program will obtain feedback from those birthing facilities participating in the pilot before implementing the system statewide. EHDI program personnel will continue to work with the top four birthing facilities currently not in compliance with state and national EHDI goals to implement a corrective action plan. Thus far the birthing facilities that have had to implement a similar plan have been receptive and found that the process helped them make positive changes.

Ongoing education and outreach will take place with birthing facilities personnel, audiologists, ENTs, PCPs and nursing staff through phone calls and emails, bimonthly tips, newsletter articles, presentations, webinars and targeted mailings. The EHDI program plans to reach out to the newborn dried bloodspot program in the next reporting period to explore a partnership to educate OB/GYNs about newborn hearing screening so they can in turn educate pregnant mothers about newborn screening.

The Iowa EHDI Chapter Champion, Dr. Sullivan, will continue to educate medical students and nurse practitioners about newborn hearing screening and their role in recommended timely follow-up during their education at the University of Iowa. Dr. Sullivan and the IDPH EHDI program have reached out to the other medical college in Iowa, Des Moines University (DMU), to provide education and outreach to their students. However, the DMU administrators have not been responsive to EHDI program personnel, including AAP EHDI Chapter Champion, phone calls or emails. Dr. Sullivan and the state EHDI coordinator will attempt to reach out to the medical school again during the next reporting period through relationships with administrators from the public health program.

In the beginning of 2015, EHDI program personnel will reach out to local midwives to assemble a small workgroup that also includes a couple of parents whose infants were born outside of the hospital. EHDI personnel will explore attitudes, beliefs, and barriers that may impact out of hospital birth families from obtaining a screen for their infant and review current resources to ensure they are sensitive to their needs. The EHDI program will determine if midwives could benefit from a second mailing that summarizes the differences in screening rates between infants born in the hospital and infants born outside the hospital.

Tele-audiology will be piloted in two AEAs in the spring of 2015. The lead EHDI Audiologist and EHDI coordinator are in the process of exploring online and in-person diagnostic ABR training and mentorship support.

The EHDI program has had the opportunity to work ahead on a couple of activities scheduled to begin in the next reporting period. One activity was to update the current EHDI website. The EHDI coordinator worked with an intern over the summer to redesign the website home page and re-organize the content by page (Professionals, Families, EHDI Advisory Committee and Contact Us). A new intern was recently hired and is scheduled to begin in January 2015. One of the tasks this individual will complete is finalization of all content and to meet with the IDPH information technology personnel to begin the redesign.

The second activity EHDI program personnel began working on was exploring the use of Title V agencies to get infants back in for a hearing re-screen. Title V agencies already reach out to all Medicaid families to inform them about the Early and Periodic Screening, Diagnostic and Treatment program. Extending assistance to help Medicaid families schedule hearing re-screens seemed like a natural fit. The EHDI program looked at counties in the state with the greatest numbers of infants lost to follow-up and looked to see if those infants were served by the Title V program in that community. Approximately 39 percent of the families contacted by Title V did not receive recommended follow-up hearing screens or assessments. Upon further review of successful contacts by the Title V program to the EHDI LTF/LTD families, it was determined that it took an average of 50-52 days to reach them which is many more days beyond contacts initially made by the EHDI program which can be as early as 15-20 days. The EHDI program decided not to pursue this relationship further other than to request Title V programs inquire about hearing screening when assisting families with other screening, assessment or treatment needs. The EHDI program did reach out to the Women, Infants and Children (WIC) program to see if they would meet as the two programs have discussed in the past to further explore a partnership. WIC personnel agreed to meet. Further analysis will take place with the goal of piloting the use of WIC clinics for their assistance in scheduling hearing re-screens or conducting hearing screening if the equipment is available.

All activities will be analyzed and evaluated for effectiveness prior to statewide implementation.