

Reducing Loss to Followup after Failure to Pass Newborn Hearing Screening - Iowa

NON-COMPETING CONTINUATION (NCC) PROGRESS REPORT for the reporting period April 1, 2011-March 31, 2012

Note to Reviewers: As instructed in the guidance, we predominantly reported on April 1, 2011 – March 31, 2012. However, many additional activities were completed April 1, 2012–December 31, 2012 including conferences and educational events. Conference and educational event details appear in paragraphs labeled as “Upcoming Budget Year”.

1. Project Identifier Information

- a. **Grant Number:** H61MC00031
- b. **Project Title:** Universal Newborn Hearing Screening
- c. **Organization Name:** University of Iowa Hospitals & Clinics (UIHC), Child Health Specialty Clinics (CHSC)
- d. **Mailing Address:** 100 Hawkins Dr., Rm 247-CDD, Iowa City, IA 52242-1011
- e. **Primary Contact Information:**
 - i. Debra Waldron, MD, MPH, FAAP
 - ii. 319-467-5009
 - iii. Debra-waldron@uiowa.edu

2. Accomplishments and Barriers

Accomplishments – Iowa’s statewide *Early Hearing Detection and Intervention (EHDI) System of Care (SOC)* works to ensure that all children with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention, and family support. The EHDI program is also dedicated to providing unbiased support to families of children who are deaf or hard of hearing (D/HH).

This project has centered on assuring and facilitating timely, comprehensive, coordinated, culturally competent care for children 0-3 years of age who are at risk for developing or have been diagnosed with hearing loss. Our medical home initiative focuses on securing access for these children and their families to care coordination and community-based services in an efficient and family-centered manner. Ultimately, our work will reduce loss to follow-up rates for infants and toddlers in the Iowa EHDI SOC and increase access to appropriate services which will promote healthy child development. We work to foster communication and collaboration among key stakeholders including primary care providers (PCPs), community health centers, families, Part C IDEA (Early Intervention/Early ACCESS (EA) in Iowa), care coordinators, specialists including audiologists and otolaryngologists (ENT), Early Head Start, Home Visiting programs, family advocacy groups, and alternative health practitioners. Child Health Specialty Clinics (CHSC), Iowa’s Title V Program for Children and Youth with Special Health Care Needs (CYSHCN), continues to work closely with Iowa Department of Public Health (IDPH) to administer Iowa’s EHDI program. CHSC is primarily responsible for Long Term Follow-up (LTF) activities which begin after a child did not pass (DNP) two screens. LTF activities include diagnostic audiology, amplification, enrollment in EA and Guide By Your Side (GBYS) family support. We also monitor children that are at risk for delayed-onset or progressive hearing loss. The main focus of IDPH (CDC-funded project team) is on Short Term Follow-up (STF) activities; follow-up after the initial birth screen (BS); and rescreen for babies who miss or DNP BS, the overall data surveillance system and its upkeep. CHSC provides funding to IDPH via a subcontract to support a portion of the STF tasks.

Together we work to strategically disseminate and exchange information between the medical specialty providers to ensure effective partnering with medical homes. This grant ensures that community-based services for children with hearing loss are available, that families are offered them early and often and can access them easily. This includes access to diagnostic assessment, entry into early intervention, and family support that empowers parents to make personal choices for their child's communication and hearing needs.

Individual records are reviewed to determine: 1) if diagnostic results are present, and have been entered; 2) amplification information is present (if applicable); 3) status of enrollment in EA is determined; and 4) documentation is present that family support services have been offered and subsequent enrollment into the GBYS program. The LTF processes are discussed in detail in the Case Management Module.

OZ/eSP is the designated state system for hearing information on all children born in Iowa. Children born outside of Iowa are entered as they become known. Creation of new Case Management (CM) functionality in OZ/eSP was delivered in March 2012 and is outlined in more detail below.

Delayed onset or progressive hearing loss risk factor (RF) efforts: In 2011, 3511 children with RF were identified based on Joint Committee on Infant Hearing (JCIH) indicators. Currently letters are sent via U. S. Mail (when the child is 3 months old) to families and Primary Care Providers (PCPs) reminding them that the child needs to have an audiological assessment by 6 or 24-30 months of age depending on risk indicated. Iowa EHDI and EA answer questions from parents and PCPs to ensure that coordinated follow-up care is provided and ensure that children receive the follow-up care they need. Included with the letter to PCPs is a fax back form asking for information about assessments performed and updated PCP and family contact information. Eight hundred seventy-one forms (25%) were received back. Thirty-nine percent indicated they were not the child's PCP and did not indicate a new PCP, 22% provided new PCP information, 14% indicated their intention to follow-up on the required testing in the future, 7% indicated new contact information for the family, and 6% indicated that children had been back in and provided diagnostic assessment results, three children DNP the diagnostic assessment. The vast majority of Iowa PCPs are ensuring the required follow up. Ten percent of faxback forms were returned blank or with birth screen results. Follow-up calls are made to PCPs for further clarification when their responses indicate a lack of knowledge or concern about the RF. Opportunities have been identified to work with birthing hospitals when identifying risk factors as parental reports on 2% of the forms indicate the child does not have the listed RF. In addition, the letters and fax back forms also serve as a springboard for the discussion of hearing health in the medical home as PCPs and parents are aware of and can have meaningful discussions about hearing healthcare at each well-child visit to discuss communication and language development. PCPs note that they have had a specific conversation with the parents and that *"there are no concerns about hearing at this time."*

In June 2011, Hector Garrido was hired as an EHDI Family Support Liaison (Support Services Specialist) at the University of Iowa, CHSC. Although Mr. Garrido was not the parent of a child with a hearing loss, he was hired to ensure contact with the Latino/Hispanic community in Iowa and develop GBYS family-to-family parent support for this population. Our efforts to hire a Latino GBYS Parent Guide continued to be a barrier, so our next best solution was to hire someone highly connected to the Latino community.

In November 2011, the Iowa Chapter of the American Academy of Pediatrics (IA-AAP) along with Partnership to Improve Child Health in Iowa (PI CHI) was approved by **American Board of Pediatrics (ABP), Maintenance of Certification (MOC)**, for a Performance in Partnership, MOC Part 4 project. **Title:** *Ensuring follow-up for children at risk for delayed-onset or progressive hearing loss (HL)*, (see Goal 2, Objective 2.1, ii). Certification is open to any practicing PCP in Iowa. The project aim is to ensure all children ages 0-30 months that passed their BS and have RF for delayed-onset or progressive hearing loss receive follow-up that is consistent with the JCIH recommendations. PCPs will be able to identify all children in their practice who have a hearing loss or are at risk for delayed-onset or progressive hearing loss by 24-30 months of age and provide care management that emphasizes: pre-visit planning;

assessing patient progress toward treatment goals; and addresses barriers to these goals. PCPs will also be taught the steps to produce a self-care family plan that includes audiologic follow-up and referral to GBYS family support. Completion of the IRB review process led to delays in curriculum development. Additional work planned for 2013-2014 is PCP enrollment and support. Planning and toolkit development were accomplished in early 2012.

In December 2011, we were invited to participate in a **Tele-Audiology Learning Community (LC)** that is being initiated with several states pursuing the use of distance technologies to provide diagnostic and other audiological services for children with or at risk for hearing loss (Objective 3.2). This will provide an opportunity for participants to share successful strategies and to work together to address challenges. The information and products resulting from the LC will be used to improve current processes and disseminated to NCHAM's broader audience.

Iowa EHDI continues to participate in the **Early Hearing Detection and Intervention (EHDI) PALS (Pediatric Audiology Links to Services)** working group providing parent/family and EHDI Coordinator perspectives. EHDI-PALS is a web-based system to help parents, hospital personnel, and physicians find appropriate pediatric audiology facilities that will meet an individual child's needs. The EHDI-PALS Directory will include facilities that have the appropriate equipment to serve children under five years of age, especially the birth-to-3 year population, and employ licensed audiologists.

EHDI Chapter Education & Training grant was awarded to the IA-AAP on October 17, 2011. The ultimate goal of IA-AAP and CHSC was to improve the state EHDI SOC, so children with or at risk for hearing loss can achieve optimal health and well-being. This funding provided opportunities to achieve the following goals and objectives: 1) increased PCP knowledge on the Iowa EHDI SOC; and 2) increased linkages between the clinical care system (PCPs) and the family support/care coordination system. This was achieved through the creation, coordination, and dissemination of a multi-media educational message for PCPs on the Iowa EHDI SOC (see Goal 1, Objective 1.4 for details).

On February 13, 2012, we presented a session at the **Association of Maternal and Child Health Programs (AMCHP)** Annual Conference in Washington, DC, titled *"Using Quality Improvement Methodologies to Engage Medical Homes in Early Hearing Detection & Intervention Programs"*. This presentation highlighted how we use the Model for Improvement and Plan-Do-Study-Act (PDSA) cycles to test small changes, engage/educate providers and the community to improve early identification, intervention and family support for children with a hearing loss. The presentation concentrated on work done by our Medical Home Implementation Team (MHIT) to create an EHDI Medical Home Toolkit for PCPs building on skills learned during our NICHQ initiative. Creating an effective EHDI program for CYSHCN to ensure babies with a hearing loss are identified early, receive timely/appropriate audiological, educational, medical intervention and family support is a challenging and pressing responsibility for Title V programs.

On March 9, 2012, a presentation was made to Grupo Manantial, at the Children's Center for Therapy in Iowa City. This support group consists of approximately 30 Hispanic families who have a child aged 0-5 years with a developmental disability. Hector Garrido, EHDI Family Support Liaison, conducted the presentation entirely in Spanish. It included information about Family to Family Iowa (F2F Iowa); what it is and how it can help families who have CYSHCN. F2F Iowa is made up of over 25 different family support and educational organizations for CYSHCN. It is a direct support to families navigating the health system and has been designed to connect families to community services and teach self-advocacy skills to families with a child who has special needs. The presentation also reviewed the objectives of Iowa EHDI; emphasizing the importance of early identification and intervention of hearing loss. Copies of the presentation file were provided in English & Spanish.

A new OZ/eSP **Case Management (CM)** module was implemented in March 2012. It allows us to gather new information on contacts made by follow-up staff in order to identify the status of a child in the hearing path.

Information is collected on the kind of contacts using standard pull-down lists to create consistency in our reporting. It captures: Event; Email, Phone, Fax, Faxback form, Text; To/From (role that initiated/received the contact); EHDI, Audiologist, PCP, Family, ENT, EI/EA, GBYS, etc.; Reason (location in the hearing path); BS, Outpatient Screen (OP), audiological assessment (AA), risk monitoring, etc.; Result (of the contact): updated addresses, referred/enrolled in services, parental report, refused screening/assessment, etc. Work continues to complete requirements for detailed reports to meet the needs of the program and reduce manual counting work. The addition of a field called "Next Follow-up Date" will allow us to easily query the status of the database and allow us easier access to this information. Data from the new CM module on babies born in 2011 revealed: Type of contact: 72% via phone call, 13% via letter, 11% via email, 5% via fax. Calls were made to: 31% to PCP/Medical Home; 13% to families; 13% to Audiologist (AEA or Private); 5% to ENTs. Six percent of calls were made by GBYS. Phone calls are made when information is incomplete or unclear. By contacting families we are able to inquire about current needs, care coordination and assist with next steps. Phone calls were also made to audiologists to discuss OZ/eSP documentation responsibilities and the importance of timely and accurate data entry. Our Parent Support Coordinator calls families to tell her personal story and bring the families in for a further hearing workup. We also clarified the current diagnosed hearing status of the child and asked about next steps or family concerns that we needed to be aware of and could help resolve. Phone calls were made to medical homes (PCP indicated in record), ENTs, and Area Education Agency (AEA) Audiologists when necessary to understand who is providing and following the child's care. Calls to offices frequently require leaving messages. Twenty-five percent of messages left for the medical home were returned. All information about a child's hearing healthcare must be documented in their record in OZ/eSP. An example CM note is: "Called ENT office. Spoke with nurse, she pulled records & called back. At 1:55 pm she reported that on 12/16/11 child had bilateral tube surgery. 1/31/2012 diagnosed with bilateral chronic otitis media. His next appointment is 6/25/2012 to have tubes checked. Dr. XXX will be added as care provider in OZ." However, when professionals do not get a response from the family, progress in the case stops until LTF investigates to discover the next step in the hearing path. PCPs relate that families may not show up for appointments and, at times, language barriers may be contributing to patient's full understanding of the process and importance of hearing testing.

A **Vivosonic Aurix™ Hearing Screening system (AABR)** was purchased for Marshalltown Medical & Surgical Center (MMSC) in Marshalltown, IA. This community hospital with a Level II NICU had an annual birth rate of 527 in 2011. Placing this screener with MMSC will make OP re-screens more accessible to families resulting in a more efficient follow-up system and lower lost to follow-up rate. With this placement, all hospitals in Iowa with a NICU now have access to appropriate equipment. The newborn screening policies have been updated for this hospital following the current JCIH recommendations. Babies who refer on OAE from the well-baby nursery will be rescreened with AABR and OP rescreens can also be tested on a timely basis. This facility reports a significantly reduced number of missed infants from 2011 (26 infants) to 2012 (5 infants). State data showed a reduction in their annual refer rate of 13% to 12% with a 2012 fourth quarter refer rate of 10% which is the lowest quarter in both years.

Work was completed on the **Iowa Loss & Found video** featuring parents of babies that DNP the BS. The video was customized to include information from EA Iowa, Iowa GBYS and Iowa EHDI. Loss & Found will be included in our Toolkit and is posted on YouTube on the IA-AAP channel: <http://www.youtube.com/watch?v=RUFCLarSa4>.

Iowa EHDI was selected by the National Center for Cultural Competence (NCCC) and the National Center for Hearing Assessment and Management (NCHAM) to participate in the **Community of Learners (COL)** leadership to advance and sustain cultural and linguistic competence in EHDI programs. In this COL project we are developing a strategic plan in order to ensure cultural competence in all EHDI practices.

Barriers – The most significant barrier was the resignation of Peggy Swails in September 2011, our EHDI LTF Coordinator, a full 1.0 FTE (see **Significant Changes** section below). In March 2012, we hired a replacement who resigned after 3 months. Staff vacancies and limited staff time continue to be barriers.

OZ/eSP, the designated statewide database presented several barriers: There was not an easy way to consistently document contacts made to support detailed data analysis of where a child was in relationship to screening and diagnosis. Accessibility is limited to specific providers and therefore information is not always regularly or accurately entered in a timely manner. Delivery of OZ/eSP enhancements will help us to streamline follow-up processes, which will greatly reduce staff effort. Data sharing continues to be a challenge between EHDI and EA due to HIPAA and FERPA restrictions, although conversations to resolve issues are continuing. The new CM module will allow us to train current users to be able to easily identify where the child is in the hearing path, what contacts have been made by when, and what the next step should be to get them to diagnosis (by three months of age), amplification (if applicable) and enrolled in EA and GBYS parent support by 6 months of age.

3. Goals & Objectives and Plans for Upcoming Budget Year

Goal 1: By March 31, 2014, 95% of Iowa infants (including out of hospital births) who miss, had incomplete, or Did Not Pass the birth screen, will receive screen and re-screen (if necessary) by one month of age.

In 2011 (preliminary data), out of 38,054 births; 98% were screened, 92% passed at birth, 6.4% did not pass or were missed. Of the 6.4% (2451) that did not pass/missed birth screen, 86% (2101) received an outpatient screen, 75% (1850) passed their outpatient screen and 10% (251) did not pass at outpatient.

- **Objective 1.1:** Assure all Iowa EHDI standards for early screening protocols are met as required by Iowa Code.
 - a. **STATUS: Ongoing.** Contract deliverables to IDPH related to STF and LTF are being delivered. These deliverables include access to OZ/eSP for the purposes of follow-up. Data is used for identifying children for referral to diagnostic audiology, EA, GBYS family support program for all children who missed or DNP their hearing screening, as well as those that passed their BS and have RF for delayed-onset or progressive hearing loss. CHSC provides IDPH with funding for a 0.70 FTE to assist with STF, and expenses associated with data analysis (procure, clean, aggregate, and analyze) for LTF in OZ/eSP.
 - b. **Upcoming Budget Year:** Subcontracts will continue with IDPH related to STF.
- **Objective 1.2:** Assure protocols are developed and used appropriately for timely reporting of screening results to families and medical homes.
 - a. **STATUS: Ongoing.** Deliverables related to STF are on track. Protocols are currently in use. Follow-up phone calls to families, PCPs, and audiologists for children who missed or DNP BS and subsequent OP screen are occurring in a timely fashion. Work will continue specific to STF at IDPH. Protocols will be reviewed and updated as identified.
 - b. **Upcoming Budget Year:** Subcontracts will continue with IDPH related to STF.
- **Objective 1.3:** Promote importance of early identification to families, providers, and other stakeholders.
 - a. **STATUS: Ongoing.** Iowa EHDI program continues to disseminate materials to all stakeholders about importance of early identification of hearing loss via in-person hospital site visits, emails, newsletters and brochure mailings as well as letters and phone calls to families, PCPs, audiologists and EA. Quality improvement methodologies (PDSA Cycles) were used to help us understand what information is needed by PCPs, when they need it and in what format they prefer it. PDSA cycles were completed, change was identified, and feedback was used to develop the toolkit. The outcome was the development of the EHDI Medical Home Toolkit.
 - b. **Upcoming Budget Year:** Future work will include distribution of the toolkit to several hundred medical professionals in Iowa to educate them on importance of early identification of hearing loss. Updates to the current Iowa Family Resource Guide and the Loss & Found video will be included. Membership in F2F Iowa Governance Council will continue. EHDI, Iowa Hands & Voices and GBYS are Governance Council members.

Future work will include identification of additional stakeholder groups (Visiting Nurses, Early Head Start, and Midwives) to present about the EHDI SOC.

- **Objective 1.4:** Assure Iowa practicing primary care providers and those in training receive education during Grand Rounds and other professional events re EHDI System of Care from the Iowa's AAP Chapter Champion.
 - a. **STATUS: Ongoing.**
 - i. University of Iowa of Iowa Hospitals and Clinics, Pediatric Grand Rounds, Friday, September 30, 2011 (over 40 attendees).
 - ii. Presentation Title: *Can you hear me now? Iowa's Early Hearing Detection and Intervention (EHDI) System of Care (SOC).* Topics included; Parent/Family Perspective, Iowa EHDI 101, and Roles/Responsibilities of Newborn Hearing Screening stakeholders. Presenters included: Tammy O'Hollearn, Iowa EHDI Coordinator, Iowa Department of Public Health; Vicki Hunting, Parent, EHDI HRSA Project Director, Child Health Specialty Clinics; Shannon Sullivan, MD, UI Clinical Associate Professor, Iowa EHDI AAP Chapter Champion; and Mary Larew, MD, UI Clinical Associate Professor, CHSC Medical Director. Outcomes from presentations: Identical surveys were given immediately prior to and upon completion of the presentation to measure the audience's increased in knowledge from the seminars. Overall, learning was enhanced by a 13% increase in correct responses. Statistically significant learning was demonstrated in knowledge regarding frequency of hearing loss, the impact of early intervention, identification of risk factors, and the need for timely screening and diagnosis.
 - iii. Family stories are being collected by families that were assisted in their journey to deaf/hard of hearing (D/HH) world by GBYS Guides. See Winter 2012 newsletter, page 8 for one example: http://www.idph.state.ia.us/iaehdi/common/pdf/news_winter12.pdf
 - b. **Upcoming Budget Year:** The following presentations are complete, same format as outlined above for title, topics, and presenters. Additional presentations are being considered.
 - i. Blank Children's Hospital/Des Moines, Pediatric Grand Rounds, April 6, 2012 (30+ attendees)
 - ii. 2012 Iowa Governor's Conference on Public Health, April 18, 2012, *Can You Hear Me Now? Engaging Medical Home Providers on Early Intervention and Family Support for Kids With a Hearing Loss.* Presented by Vicki Hunting and Mary Larew.
 - iii. Iowa Symposium on Hearing Loss: *Impact on Children and their Families*, September 28-29, 2012. Numerous presentations by local/national speakers: Faye P. McCollister/University of Alabama (CMV), Christie Yoshinaga-Itano/University of Colorado (delayed onset hearing loss), Mark Marschark (Deaf Education), Leeanne Seaver (parent support) and Karen Putz (Deaf adult/parent perspective) as well as presentations by and for Iowa parents. Iowa Hands & Voices, GBYS training was provided to Parent and Deaf/Hard of Hearing Guides by Susan Hagarty, GBYS Program Coordinator. Link to materials: <http://iowahandsandvoices.org/event-materials.asp>
 - iv. Peoples Community Health Clinic, Federally Qualified Health Center (FQHC) in Waterloo, October 16, 2012.
 - v. Mercy Hospital in Des Moines, Pediatric Grand Rounds, October 25, 2012.

Goal 2: By March 31, 2014, 95% of children 0-3 years of age who did not pass two screens and/or have any risk indicators for late onset hearing loss, as defined by JCIH, receive the follow-up care they need, including care coordination and family support, within a medical home.

- a. **Progress: Ongoing.** In 2011, out of 38,054 births (preliminary data); there were 321 babies identified as needing a diagnostic assessment. One hundred seventy-seven (55%) of the 321 children who were followed by LTF received a hearing diagnosis by 3 months of age. Of the 321 children, there were 283 (88%) babies that received at least one diagnostic assessment; 179 (63%) of 283 children tested had normal hearing. Sixty-three (22%) were identified with permanent hearing loss; of those: 50 (79%) had recommendations for amplification, of which 21 (42%) had documented amplification. Thirty-nine (13.7%) children have not yet had a diagnostic assessment recorded. Of the 39 children, all have had at least one contact documented in

the CM module of OZ/eSP. Although these children did not receive a diagnostic assessment, many had 13 to 20 contacts documented from follow-up staff. This underscores the challenges involved in LTF. The LTF phase has the largest percentage of “unresponsive” contacts. Several factors contribute to this. There are only ten Iowa Audiology providers who offer diagnostic services for infants and toddlers who have, or are suspected of having, hearing loss and four additional out of state centers located relatively close to Iowa’s borders. Frequently families must travel significant distances from their homes to attend these visits. Our ongoing work on the EHDI-PALS project will enable families and professionals to locate the hearing services for testing as well as provide a wide range of parent resources to families on what to expect with testing, amplification, and next steps. Many PCPs reported concerns in following up on not only hearing assessments, but also for well child care and immunizations. At times language barriers may be contributing to not fully understanding the process and importance of hearing testing. In 2011, we did not have a full-time LTF Coordinator and as a result experienced delays with LTF contacts.

- b. Family Support work continues by the GBYS Coordinator. Six percent of calls documented in the CM module were made by GBYS. Thirty-seven (59%) of children with a permanent hearing loss received contacts from family support via GBYS. Of the families contacted; eight were enrolled in GBYS three additional families asked to be considered for future enrollment), and one family refused participation. One family was preparing to move to Texas and we were able to refer them to Texas GBYS for support. Five families were unable to be contacted due to missing or inaccurate contact information. Additionally, parent support was also provided to 28 families whose infants DNP OP screening and six of those returned for testing after being contacted by GBYS.
 - c. We understand the importance of family to family support and are committed to providing it. In light of these unacceptably low results, we will review the strategic plan along with all the processes and procedures for GBYS. We will also review job requirements and attain recommitment from staff.
- **Objective 2.1:** Increase primary care providers’ (PCPs) knowledge of the EHDI SOC.
 - a. **STATUS: Ongoing.** MHIT was created in May 2011 to support medical homes and educate PCPs, offering guidance and support. Team included; Vicki Hunting, Mary Larew, Susan Hagarty, Hector Garrido, and Shannon Sullivan. The following projects contributed progress toward this objective:
 - i. **EHDI Chapter Education & Training grant** is outlined in detail above under accomplishments. Work supported by this grant will continue through June 2012.
 - ii. **PI CHI** is a public-private partnership that works collaboratively to support clinicians in their efforts to improve children’s health care by providing the tested tools and techniques of quality improvement. This will enable improved outcomes to help children and adolescents: develop and realize their potential; satisfy their needs; and help them to work successfully together with the professionals who interact with their families. EHDI works closely with this organization and all statewide partners. PI CHI is a member of the National Improvement Partnership Network (NIPN) that was initiated by Vermont Child Health Improvement Project (VCHIP) and includes collaborative quality improvement work from over 19 states.
 - b. **Upcoming Budget Year:** Work continues to develop and engage MHIT to support/educate medical homes in the importance of early hearing detection and followup. Iowa EHDI will continue to work closely with the IA-AAP on the EHDI Chapter Education & Training grant activities as well as the APB MOC QI project. Partnership with PI CHI will continue to grow as projects overlap.
 - **Objective 2.2:** Referral guidelines, communication plans, and expectations for access to one another exist among primary and specialty care (ENT/ORL, audiology, genetics, ophthalmology, and other health care providers).
 - a. **STATUS: Ongoing.** An Iowa EHDI Best Practices Manual is available on the website (<http://www.idph.state.ia.us/iaehdi/professionals.asp>). It is a guide to assist hospitals, birth centers, AEAs, health care providers and private practice audiologists in developing programs and written protocols for newborn hearing screening, follow-up and intervention. The manual is based upon documented best

practices and Iowa EHDI Law and Administrative Rules. Work procedures and guidelines are in place for CHSC RNs where OAE/AABR equipment resides to provide care coordination for children suspected of a hearing loss, but have not been spread to other CHSC centers. Feasibility of universal consent forms, co-management/practice management tools for practices work has not begun.

- b. **Upcoming Budget Year:** Work will begin on development of Care Coordination procedures for CHSC RNs specific to EHDI to ensure they are culturally competent, family-centered and non-biased. Work to educate PCPs on the best practices for diagnostic evaluation support, reminder calls and pre-visit instructions will continue. Many of the items listed under this objective will be included in the EHDI Toolkit. Work towards implementation (and roll out to all stakeholders) of CM module for OZ/eSP continues. Letters are being developed to send to PCPs and families when it appears the family will not return for their diagnostic assessment. Parent to parent calls will be made by our GBYS Program Coordinator as a final effort to get families to return for testing.
- **Objective: 2.3 EHDI families receive necessary care coordination through the medical home.**
 - a. **STATUS: Ongoing.** Process/procedures are developed for LTF to offer coordinated care to families, when their child DNP their OP screen or audiological assessments. In addition we directly contact providers to inquire about hearing health and to ensure all information is documented in OZ/eSP. CHSC Regional Centers with OAE and AABR equipment have procedures in place to provide information to medical homes from OZ/eSP when needed. Spread to other centers has not begun. Information on following infants with risk factors is included in Accomplishments section above.
 - b. **Upcoming Budget Year:** Work on information to provide medical professionals and families about insurance coverage will be included on our Iowa EHDI website. Iowa EHDI will continue to work closely with the IA-AAP on the EHDI Chapter Education & Training grant activities as well as the APB MOC QI project. We will re-evaluate the necessity of purchasing one OAE screener by March 31, 2013. Work on care plan protocols for PCPs and care coordinators that are culturally competent, family-centered and non-biased will be completed through our participation in a Community of Learners (COL) from National Center for Cultural Competence (NCCC), and the National Center for Hearing Assessment and Management (NCHAM). This work will focus on leadership to advance and sustain cultural and linguistic competence in EHDI programs.
- **Objective 2.4: EHDI families receive family support through the medical home.**
 - a. **STATUS: Ongoing.** Work on this objective is in progress and is included part of our MHIT Toolkit for PCPs. PDSAs are in progress to assist medical professionals to ensure family support (GBYS) and community support is offered in an unbiased way.
 - b. **Upcoming Budget Year:** MHIT will continue work with medical homes to ensure parents are provided with non-biased information about parent-to-parent, family and community based services and support. This work will include articles written by Shannon Sullivan, for the IA-AAP and Iowa Academy of Family Physicians (IAAFP) newsletters, websites, etc. Work continues every day as we talk to Medical Homes one-on-one while following up on children at risk or diagnosed with a hearing loss.

Goal 3: By March 31, 2014, 95% of children 0-3 years of age with documented hearing loss will have access to the community-based services they need and their families choose, in a timely, efficient, effective, and family centered manner.

- **Objective 3.1: Enhance collaboration by delineating roles and responsibilities and establishing accountability among EHDI stakeholders, e.g. primary care providers and other medical home staff; Early Head Start; Home Visiting Programs; Part C, IDEA (Early ACCESS, etc.).**
 - a. **STATUS: Ongoing.** Early work on this objective related to Early Head Start and Home Visiting Programs has begun. PCPs, other medical professionals, and EA will benefit from the work already begun by MHIT and the distribution of the EHDI Toolkit. Pediatric Grand Rounds presentations to Iowa's three major hospital systems and an FQHC have begun to lay the groundwork for understanding roles/responsibilities for children with a hearing loss.

- b. **Upcoming Budget Year:** In November 2012, Jeff Hoffman from NCHAM/Early Childhood Hearing Outreach (ECHO) program provided training to Early Head Start and Community Action participants including a ‘hands-on’ practice session at an infant/toddler room. Nick Salmon, MS, CC-A/Iowa EHD Technical Assistance support provided Iowa specific information and instruction about Iowa laws on reporting results of screenings to the IDPH. Work begins on collaboration and re-establishment of partnerships with Early Head Start, Home Visiting and Part C/EA programs to clarify roles and responsibility within the EHD SOC.
- **Objective 3.2:** Families will have community-based options available for completing timely audiological follow-up and at least 95% of children who did not pass two screens will receive diagnostic testing by 3 months of age.
 - a. **STATUS: Ongoing.** In 2011, 177 (63%) of children who received diagnostic testing did so by 3 months of age. This reflects a 3% improvement from 2010 results. While work in the area of performing remote (Tele-Audiology) ABR evaluations for children suspected of having a hearing loss began in November 2010, referrals continue to be low. This service allows audiologists to perform diagnostic ABRs remotely with the assistance of a trained healthcare professional located at the remote site.
 - b. **Upcoming Budget Year:** Next steps include: (1) Ongoing review of current, timely data entry of diagnostic and recommendation information entered into OZ/eSP by Audiologists after diagnosis. (2) Participation in NCHAM Tele-Audiology LC as described in Accomplishments section. (3) Finalize our best practices guide for dissemination. (4) Develop marketing strategies to inform providers on the availability to perform hearing diagnostic tests via telehealth equipment.
 - **Objective 3.3:** Families will have community-based options available for completing timely audiological follow-up and at least 95% of children who have diagnosed hearing loss will receive amplification (if family choice) by 6 months of age.

EHDI is working to standardize our processes so that all children with permanent hearing loss who receive amplification have that data recorded in eSP.

 - a. **STATUS: Ongoing.** Unfortunately reporting of amplification information is not required under Iowa law. Of the 63 children with PHL, 50 (79%) had recommendations for amplification. Yet, only 21 (42%) had the amplification fitting data in eSP/OZ and four parents refused amplification. One-on-one followup calls to Audiologists are helping us to have better data in the area of amplification documentation. These upgrades to our system will greatly enhance our current time consuming and partially automated process to identify these children. Information on importance of timely evaluations in the EHDI Toolkit.
 - b. **Upcoming Budget Year:** Create training manual and conduct sessions for implementation of new CM module in OZ/eSP throughout Iowa to Audiologists. Continued MHIT work to educate Iowa EHDI SOC stakeholders about importance of monitoring results and followup. Information on the importance of timely evaluations, amplification, and documentation in OZ/eSP will also be provided in our EHDI Toolkit. Efforts focused on awareness of options for families on eligibility and benefits provided by public programs and private financing resources for securing amplification will be included in Iowa EHDI website redesign as well as including links to this information to our website from IA-AAP and IAAFP websites.
 - **Objective 3.4:** Infants and toddlers with hearing loss are enrolled in early intervention services by 6 months of age.
 - a. **STATUS: Ongoing.** Communication with providers to ensure awareness of eligibility and importance of EA and care coordination services. This includes email messages as well as articles about the importance of early identification and follow-up for those suspected of hearing loss. Plans are underway to meet with community groups to educate them on the importance of early hearing detection and intervention and where they can go to get the support they need (family support, testing, diagnostic, etc.). Implementation of the OZ/eSP CM enhancements will enable reporting information related to enrollment in EA. EHDI is working to standardize our processes so that all children with permanent hearing loss are consistently referred to EA and GBYS by 6 months of age. Documentation and communication of the EA status is shown by CM notes written by LTF staff in ESP/OZ. Referral, enrollment or refusal of EA services generated one hundred-twelve

(5.3%) CM notes. Thirty-five children with permanent hearing loss were referred to EA services. Twenty-eight of these qualified for EA services and have the IFSP date documented in eSP.

- b. **Upcoming Budget Year:** Continue to educate stakeholders on early intervention support options. Implement, educate and roll out training on CM module statewide. Ensure GBYS and Hands & Voices Parent Leaders are included as members of the EA service team to provide input to IFSP process.
- **Objective 3.5: Families of children who are deaf or hard of hearing will have access to culturally competent family support services and the information they need to make informed choices, including all communication options.**
 - a. **STATUS: Ongoing.** Efforts began to connect with the Latino/Hispanic community in Iowa and work toward development of parent-to-parent support (GBYS) for this population. Iowa EHDI has an ongoing relationship with Iowa Hands & Voices and F2F Iowa. Parent and Hispanic representatives attended the 2011 EHDI Partnering for Progress conference. Parents and a GBYS D/HH Adult Guide attended the 2011 Hands & Voices Leadership Conference. One parent has participated on the National EHDI Meeting Planning Committee for the last four years. Iowa GBYS Guides are represented on boards of Iowa Hands & Voices, Iowa Association of the Deaf, F2F Iowa Governance Council, the Iowa EHDI Advisory Council, the Iowa National Summit state team and the Iowa Board of Regents Coordinating Council for Deaf and Hard of Hearing. GBYS Guides meet with local AEAs in their home communities throughout Iowa to build relationships, and engage in conversations and education about EHDI with community leaders, legislators, Deaf Adult organizations, etc. In addition, one family received support in their native language of Spanish and three culturally Deaf families have been supported through our GBYS Deaf Guide in their native language of ASL.
 - b. **Upcoming Budget Year:** Iowa EHDI sponsored the 2012 Iowa Symposium on Hearing Loss; *Impact on Children and Their Families*. Registration and travel expenses were paid for Iowa GBYS Guides. A parent presented a session at the 2012 EHDI Meeting in St. Louis. We will continue presentations to populations in Iowa where English is not their first language to spread understanding of importance of early identification of hearing loss and follow-up activities. Continue to involve parent leaders, Iowa Hands & Voices, F2F Iowa and other Iowa stakeholders in systems building committees at state and local levels and provide compensation for parent leaders to participate. Continued participation in the NCCC COL to enhance our linguistic competence in Iowa EHDI. We are working to forge partnerships with diverse groups while developing policies, procedures and EHDI best practices that are culturally competent.

4. Significant Changes

On September 14, 2011, our LTF EHDI Follow-up Coordinator resigned. A new candidate was selected in March 2012, but resigned after 3 months. A new Coordinator was hired October, 2012.