

**A. Project Identifier Information**

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**Project Title:** Universal Newborn Hearing Screening Program  
FY 2016 Non-competing Continuation (NCC) Progress Report

**Organization Name:** The University of Illinois at Chicago (UIC)  
Division of Specialized Care for Children (DSCC)

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## C. Experience to Date

### I. Purpose:

The purpose of this project is to support Illinois EHDI program staff efforts in improving the number of infants lost to follow-up/documentation by utilizing specific interventions such as quality improvement (QI) methodology to achieve measurable outcomes and ensure timely completion of diagnostics and enrollment in early intervention (EI).

### II. Goals/Objectives:

**Goal 1: Establish a State Level Quality Improvement Team that represents multiple stages in the EHDI continuum to address quality improvement, system development and sustainability at the statewide and community level.**

**Objective 1:** Identify and engage state level project team members with decision-making authority.

**Objective 2:** A State level Project team will become familiar with quality improvement and will meet quarterly at minimum to address data sharing and system development at the larger state level.

**Objective 3:** Parent focused quality improvement leadership team that meets to address service delivery at 1-3-6 and parent to parent support and spread of activities statewide will specifically improve parent brochures, website content, and the EHDI roadmap.

### **Progress:**

Illinois Department of Public Health (IDPH), the University of Chicago- Division of Specialized Care for Children (UIC-DSCC, Title V Children with Special Healthcare Needs program) and EI team members formed a quality improvement group in Jan 2015 to identify needs and barriers in the Illinois system. This group includes by Ginger Mullin (IDPH); Gerri Clark & Esha Phatak (DSCC); Ann Freiburg & Colleen Cunningham (Bureau of Early Intervention at DHS). The meetings were held either by phone or in-person on 04/09/15; 06/03/15; 06/17/15; 08/04/15; 11/15/15. The group identified opportunities for training, education, outreach and exchange of data using a secure file transfer process to ensure timely referral and proper documentation in the database.

The group has completed Plan, Do, Study, Act (PDSA) cycles around referrals to Guide By Your Side (GBYS), education of EI service providers on services for children with a hearing loss and started a PDSA with service coordinators reporting Individual Family Service Plan (IFSP) dates to IDPH in the fall of 2014. The PDSA included that the EI service coordinators would share the IFSP information with parents' authorization with the IDPH. The PDSA was modified several times but was unsuccessful as the Bureau of Early Intervention expressed some concerns with sharing confidential information and possibly violating HIPAA, FERPA, and Part C rules and regulations in the process. This specific PDSA was abandoned in June of 2014 but with ongoing discussions with the team members, it later led to the development of automated data transfer to share child-specific information. The process of automated data transfer is currently being discussed between the Bureau of Early Intervention and IDPH and is expected to take place in the first quarter of 2016.

**Goal 2: Sustain the percent of infants who receive an inpatient hearing screening at a minimum of 97% or greater.**

**Objective 1:** Hospital screening staff exhibit competency around UNH screening by utilizing a standardized and measurable training tool (NHSTC).

**Objective 2:** Hospital screening staff who have participated in training will be aware of opportunities for quality improvement that lead to reduced loss to follow-up, including use of scripted messages and crib cards, scheduling appointments, and identifying the PCP.

**Progress:**

Illinois has 125 birthing facilities with 25% outsourcing the newborn hearing screening to outside entities. This percentage accounts for 47% of all births including Northwestern hospital, the largest birthing hospital in the state with over 12,500 births annually. Illinois has consistently met this goal for the past three years (2013-2015) with a screening rate of over 98%. Additionally, the EHDI program continues to develop strategies and provide guidance to all hospitals on improving the state newborn hearing missed rate to less than 1%.

The Illinois EHDI program has made ongoing efforts to sustain the number of infants screened at a rate of 97% or greater by promoting education on an annual basis at the hospital level on newborn hearing screening practices. One of the strategies that the program staff used is encouraging hospitals to educate and train the screeners by utilizing the Newborn Hearing Screening Training Curriculum (NHSTC) and skills competency checklist. In July 2015, a survey link was emailed to all birthing facilities to participate in the NHSTC. Out of 125 hospitals, 27 responded back indicating that their screening staff would initiate or complete the on-line standardized training before the end of the year. Each hospital chose a target month of July, August, September, October, November or December. As of December 15<sup>th</sup>, 104 screeners have completed the training on-line.

The program staff encouraged hospital staff to utilize quality improvement strategies that are highlighted within the NHSTC, e.g. scripted messages for parents, the use of crib cards, and scheduling outpatient screening appointments prior to discharge for infants who do not pass the newborn hearing screening at the hospital. Every birthing hospital in the state was provided with the modified newborn hearing screening brochures to educate parents and providers. A supply order form was posted to the Illinoisoundbeginnings website and each hospital was encouraged to order a six month supply of the free materials. In addition, follow-up regarding the hands-on skills competency checklist for screeners as part of on-going training is being shared as a quality measure with the participating hospitals.

**Goal 3: Infants who did not pass inpatient newborn hearing screening will receive outpatient hearing screening and/or diagnostic evaluation, and follow-up will be reported to the EHDI system.**

**Objective 1:** Parent friendly letters, brochures, and other materials that are culturally and linguistically appropriate and at an appropriate reading level for the population served will be used.

**Objective 2:** Quality Improvement strategies will be used to reduce loss to follow-up for infants' not passing hearing screening and discharged from NICU by referring to DSCC.

## Progress:

Illinois has seen a dramatic decrease in the loss to follow-up rates, decreasing from 80.4% in 2013 to 71.1% in 2015 (Jan-Sept). To help lower the rates, the program staff provided ongoing technical assistance to hospitals in: calibrating their hearing screening equipment annually; assisting families in scheduling an appointment for an outpatient screening prior to discharge; reporting screening results in a timely manner to assist families with next steps after their newborn refers on the newborn hearing screen; and providing complete and accurate information to the program to help keep infants' records current with updated demographic information. In addition, the EHDI program distributed a report card on a quarterly basis to all hospitals that highlights the number of babies born at their hospital; their screening, refer and missed rates; babies that came back for an outpatient or diagnostic; and infants that are still in-process.

Another strategy included a session that was held by the Illinois GBYS program at the 2015 national EHDI meeting in Kentucky. This session was designed for parents to provide their input on EHDI materials so they can be modified to accommodate parents' needs. The EHDI program received feedback on the following materials: information for parents on newborn hearing screening (brochure), next steps for newborn hearing screening follow-up (brochure), EHDI Roadmap and IDPH parent letter. The revised EHDI materials were later posted to the Illinoisoundbeginnings website for parents and professionals.

Additionally, the EHDI program staff received two-day training on quality improvement by the National Center for Hearing Assessment & Management consultants (Alyson Ward & Vickie Thompson) for the first time in November 2015. The training was designed to provide technical assistance and support to the Illinois EHDI program, specifically in the area of quality improvement which included basic methodology training, data review, process mapping and analysis, aims & measurements, strategy development, and the creation of initial PDSA cycles. After a detailed review of the Illinois EHDI program, the QI advisors provided the following recommendations: educate all staff on the basics of a successful EHDI program including the meaning of 1-3-6, refer rates, etc.; communicate roles and responsibilities of all staff to the entire team and discuss how those roles fit into the greater EHDI system; include staff in reviewing data to monitor progress; and consider a facilitated training in communication and education within EHDI staff such as Crucial Conversations, Effective People and Communication Skill Training.

The Illinois EHDI team developed a list of potential strategies for PDSA cycles. The specific PDSA cycles may include:

1. Consider developing a universal screening and diagnostic form that can be used by both IDPH & DSCC
  - a. Document which entity is completing the form
  - b. Check whether it is a screening or diagnostic result
  - c. State the time frame on the form as to when it should be returned, e.g. return to IDPH within 30 days
2. Develop a list of local audiology resources by city/county and post on the website as a resource for hospitals and families.
  - a. Provide a list of facilities that perform an outpatient hearing screening or a diagnostic evaluation to one hospital so their staff can assist the families in scheduling an audiology appointment after their infant refers on the newborn hearing screen.

- b. Provide a laminated resource lists for hospitals as an opportunity for a small test of change to monitor if there is an increase in audiology evaluations for those patients.
3. Identify audiology clinics who are not reporting in a timely manner. Pilot a project such as conducting phone meetings with one clinic to encourage timely reporting to the IDPH and referrals to EI.

The program staff anticipates that conducting one or more of the listed PDSA cycles above will help make further program improvements.

**Goal 4: Children with a confirmed hearing loss will be referred to early intervention, Title V CSHCN program and parent to parent services and the status of enrollment services will be documented in the EHDI data and tracking system.**

**Objective 1:** 90% of all infants with a confirmed hearing loss will receive an EHDI roadmap and/or Communication Options brochure after confirmation of a hearing loss

**Objective 2:** Parents of children with a newly identified hearing loss have parent to parent support in navigating the statewide system; they receive support and information related to enrollment in intervention services and DSCC, communication opportunities, and amplification options.

**Progress:**

In Illinois, all families of infants with a confirmed hearing loss receives informational packets from the IDPH via mail to educate and provide the parents with available resources, e.g. parent letter, GBYS brochure, Communicate with Your Child (brochure), DSCC brochure and EHDI Roadmap. Illinois has noticed some variation over the last three years in the number of children enrolled into EI after a confirmed diagnosis.

To increase enrollment into EI, the Illinois EHDI program continues to work on the following strategies:

- I. The IDPH refers the families of children with a hearing loss directly to the Part C (Early Intervention) local offices via fax upon notification of confirmation.
- II. IDPH works in collaboration with Title V- Children with special health care needs (CSHCN) program at UIC-DSCC to send referrals on a monthly basis for children with a confirmed hearing loss. The care coordinators then contact the parents to offer free care coordination services and to offer financial assistance if the family meets income guidelines. UIC-DSCC asks the parent if they are enrolled in EI. If the parent is enrolled, then the UIC-DSCC staff asks for the name and contact information of the service coordinator so an authorization form can be obtained for the exchange of information. If the parent is not enrolled but interested, then the UIC-DSCC staff provides contact information for the EI service coordinators based on the family's geographical area in which they reside. Parent then contacts the EI office to get enrolled into EI.
- III. IDPH works in collaboration with the Illinois GBYS program to ensure children with a confirmed hearing loss are referred to EI no later than 6 months of age. GBYS receives referrals from various sources including audiologist/ENT, CHOICES for parents, Hands &

- Voices, outreach events, part C (including contractors), parent, or via brochures. The GBYS coordinator contacts parents to see if they are enrolled in EI. If the family is not enrolled, contact information for the EI Child and Family Connections office is shared with the family that is located in the same geographical area and the coordinator encourages them to get enrolled. However, if the family is enrolled in EI, a release of information is obtained so that the IFSP may be shared with the IDPH. The information in the IFSP is also used by the GBYS guide to facilitate discussions and identify needs the family may have in the initial process.
- IV. In August 2015, the Illinois EHDI program revised (3-6) EHDI Roadmap to help guide families of children with a confirmed diagnosis by outlining next steps following a referral on the outpatient screen/diagnostic evaluation. The roadmap serves as a great resource to educate families on when to begin intervention services and it also contains national and state resources to help families get the support they need.
- V. In September 2015, the EHDI program developed another strategy to encourage audiology providers to make timely referrals to EI. By Jan 2016, the program staff anticipates that IDPH will send out packets via mail to all pediatric audiologists in the state containing reminders to refer children to EI within 7 days upon confirmation of diagnosis as mandated by federal law; ensure they have a copy of the (3-6) EHDI roadmap, supply order form to order more EHDI materials; and reporting forms to encourage timely reporting to the IDPH within 30 days.

**Goal 5: Home Visiting programs and local health department staff will be trained to screen using OAEs and will report data to the EHDI program.**

**Objective 1:** Home Visiting program and local health department staff receive training and support to provide OAE hearing screening for children 0-3 years

**Objective 2:** Reduction in loss to follow-up after failed hospital hearing screening for infants enrolled in Home Visiting programs or receiving services from local health departments

**Objective 3:** Documentation of children with progressive or late onset hearing loss for children enrolled in Home Visiting programs

**Progress:**

Illinois works with the Early Childhood Hearing Outreach (ECHO) initiative that is a part of the National Center for Hearing Assessment and Management at the Utah State University. The ECHO initiative focuses on extending the benefit of periodic hearing screening to children 0-3 years of age in a variety of health and education settings. Beginning in 2015, the Illinois EHDI program initiated a contract with Illinois State University (ISU) audiology department to provide training on OAE hearing screening using the ECHO project curriculum to Home Visiting programs (Early Hearing Start and Parents as Teachers programs) and 17 of the local health departments that expressed interest in this project. This project was designed in an effort to reduce loss to follow-up among infants who do not pass their newborn hearing screening at the hospital and fail to return for an outpatient screening post discharge. Additional benefit included that the children with late onset or progressive hearing loss will also possibly be detected at an earlier age thereby reducing the high rate of late onset or progressive loss in Illinois in the long run. To make this project more successful, the UIC-DSCC provided financial support including distributing the OAE hearing screening equipment (Welch Allyn), supplies (e.g. disposable tips) and calibration costs for the first year to all 17 departments.

Designated staff from local health departments and some home visiting programs attended a free in-person training held at Illinois State University in Normal, Illinois. These trainings covered the following material: importance of identifying hearing loss in children, hands-on experience using OAE hearing screening equipment, troubleshooting techniques (e.g. how to successfully handle common problems such as noise in the screening environment), record keeping, and reporting results to IDPH for all children 0-3 years of age. The workshops were offered on the following dates: 02/20/15; 02/23/15; 02/27/15; 03/02/15; 03/24/15; 03/31/15; 04/14/15; 09/17/15; 10/01/15; 10/15/2015; 10/29/15; 11/12/15 & 12/03/15.

Below is the summary of activities conducted in the year 2015 by the ECHO audiology team:

ACTIVITY	SPRING	SUMMER	FALL
Number of Trainings Completed	7	0*	4
Participants Trained	46	0*	20
Participants on Wait-list/Future Training List	12	14	10
Average Pre-Training Assessment Score	9.6	0*	10.37
Average Post-Training Score Assessment Score	13.9	0*	13.63
Training Evaluations Completed	48	0*	20
Documents Created	19	11	16
Phone Calls Made to Participants	75	30	175
Emails Sent to Participants	120	52	419

**Table 1: Early Childhood Hearing Outreach Initiative: Activity Dashboard Report**

\*NOTE: Due to changes in the principal investigator at ISU, the trainings could not be offered in the summer of 2015. Please see more details included in the “Significant Changes” section on page 11.

Post trainings, the staff at home visiting programs and local health departments immediately began conducting OAE hearing screenings, making appropriate referrals and reporting screening results to the IDPH for infants and toddlers between 0- 3 years of age.

### III. Provider Engagement:

#### i. Audiology Providers:

To help families locate an audiology provider close to their home, the Illinois EHDI program has made significant efforts to promote enrolling audiology providers on EHDI-PALS website. EHDI-PALS is a national resource for parents & professionals that can help locate a qualified pediatric audiologist who serves children 0-5 years of age in Illinois. To promote knowledge and awareness of this great resource, the Illinois EHDI program has made the following attempts in the year 2015:

- ✓ The program staff sent a letter to all pediatric audiologists in the state containing information on EHDI-PALS and encouraging them to register.
- ✓ A flyer on EHDI-PALS was created and emailed to all audiology providers containing information on how to register on EHDI-PALS and remind the registered facilities to keep their profiles updated.
- ✓ The program staff made an additional effort to advertise EHDI-PALS website through the Illinois GBYS program quarterly newsletter. An article was shared with the families so they can encourage the audiology providers that they work with to register on EHDI-PALS website if they have not signed up.

ii. EHDI Chapter Champions:

The EHDI program staff continues to hold monthly meetings (Physician Task Force) to increase involvement of the Chapter Champions in EHDI related activities and to give them an opportunity to provide their feedback on ongoing projects. It also encourages other ideas that might be helpful in addressing some of the challenges that the program faces with reducing loss to follow-up rates in Illinois. Team members worked on several projects during these meetings including creating educational articles for families and physicians; these projects are outlined in the section under “Listing of Publication and Other Materials” on Pages 15-16.

IV. Achievements:

- i. Public Act 099-0424, the Cytomegalovirus Public Education Act, was signed into law on August 21, 2015. Illinois is now among the six states in the nation to participate in this initiative. The legislation requires birthing facilities to provide cytomegalovirus (CMV) educational materials and newborn testing options to parents.
- ii. The UIC-DSCC distributed newborn hearing screening and follow-up brochures that are culturally and linguistically appropriate and at an appropriate reading level to all hospitals to help educate parents on timely screening and follow-up services. These brochures are available in multiple languages including English, Spanish, French, Arabic and Polish. Addition of Arabic and French this year.
- iii. Established strong working relationship with 17 local health departments that expressed interest in conducting OAE hearing screenings for children between 0-3 years of age. The designated staff at each department has been successfully trained with hands-on training. In addition, as of Dec 15, 2015, all screenings results have been reported to the IDPH via fax, email or mail.
- iv. Webinars and statewide “calls for all” provided by IL GBYS program for families to provide information on EHDI related issues such as amplification and communication options and enrollment in DSCC and EI services (see a list of webinars/calls under section “Listing of Publications and Other Materials” on Page 15).
- v. UIC-DSCC supported hotel expenses for two presenters and a workgroup evening session at BRIDGES (two-day conference) in June 2015 that is designed for early intervention professionals. The purpose of this conference is to create the bridge between providers that specialize in helping families with deaf or hard of hearing infants or toddlers. The event allows professionals to network and pursue professional development.
- vi. The IDPH and UIC-DSCC co-sponsored a one-week program in June 2015, called the Institute for parents of children who are deaf or hard of hearing. The institute provides information and support to families, so parents can learn about their child’s individual strengths and needs and can make informed decisions on behalf of their child who is deaf or hard of hearing. There were 26 families that participated in 2015.
- vii. In 2015, over 70 families of children with hearing loss have been referred to the IL GBYS program and over 60 that have been served or are currently enrolled.
- viii. As of Dec 15<sup>th</sup>, approximately 37 facilities in Illinois are registered on EHDI-PALS website. This number has increased from 18 facilities since the beginning of 2015.
- ix. As of Dec 15<sup>th</sup>, a total of 104 hospital newborn hearing screeners have been trained on NHSTC. This number is in addition to 400 screeners that attended this training in 2014.
- x. Starting in summer of 2015, IDPH gained access to various databases such as the Illinois Healthcare and Family Services MEDI (Medical Electronic Data Interchange) database; I-CARE (Illinois Comprehensive Automated Immunizations Registry Exchange); and Cornerstone (case management system which contains information on EI clients, services authorized, and other case

information). Access to the listed databases enabled the EHDI program to locate children that are enrolled in Medicaid and also allowed the EHDI program staff to access information on primary care providers and most current demographic data. The program staff anticipates this will greatly reduce the number of families that are lost specifically due to missing or incorrect contact information (such as disconnected phone numbers, change of address, changes in medical home, etc.).

- xi. The annual hospital survey has been completed by 116 facilities in the year 2015. The information provided by the hospital personnel helped with keeping the EHDI database (Hi-Track) up to date with most current information on the primary contacts, hospital liaisons, nurse managers, and backup personnel at each facility.

#### V. Barriers:

- i. **Staffing Shortages:** The state of Illinois is in a budget crisis and hiring has been significantly limited for the partnering agencies and private diagnostic and intervention service providers. Independent contractors who provide diagnostic and intervention services for infants and toddlers are in limited supply. The shortage is due to the lack of training programs for graduating qualified providers and providers being unable to continue contractual services with the state due to delayed payment for service. Numerous staff changes over the past year have also led to issues with collaboration that impact data sharing, system development, and planning for sustainability.
- ii. **High staff turnover at the hospital level:** Illinois has experienced a high turnover of hospital based screeners and reporters in the recent years. This indicates an ongoing need for technical assistance and training newborn hearing screeners to ensure best practices are being followed. Lack of training on a regular basis has resulted in high refer rates (10% or above) at some hospitals. To assist those hospitals with lowering their refer rates; the EHDI program staff has conducted on-site visits to provide additional guidance and technical assistance by brainstorming strategies to address their specific needs.
- iii. **Lack of awareness among new parents regarding importance of follow-up screening/diagnostic evaluation:** There is an ongoing need for increasing public awareness of the importance of following up when a newborn does not pass their initial hearing screen at the hospital. To help raise awareness, the Illinois EHDI program has modified the Illinois soundbeginnings website to include additional information on newborn hearing screening and follow-up. In addition, the EHDI program staff has modified the educational materials (brochures, newsletters, crib cards) so they are available in different languages (English, Spanish, French, Polish, Arabic).
- iv. **Delays in accessing database (Hi-Track) at the IDPH:** Several team meetings with the management have been held during this project period to discuss progress of an interagency agreement between the UIC-DSCC and IDPH which remains in process. After a recent meeting in early December 2015, it was decided that this revised agreement will again be shared with the legal department at the IDPH by the end of December, 2015. The program staff anticipates that UIC-DSCC will have access to the EHDI database by the end of first quarter of 2016.
- v. **Reporting:** State legislation in Illinois mandates newborn hearing screening and reporting by hospitals and professionals who provide follow-up. However, there are no monetary incentives or consequences for facilities and professionals who do not report follow-up results. The EHDI program staff has noticed some providers that continue to advocate for the “wait and see” approach and others that conduct an evaluation in a timely manner but are not reporting screening/diagnostic results to the IDPH within 30 days. The “wait and see” approach results in

delays in identifying hearing loss at an early age and affects timely enrollment into EI. To address this issue, the program staff has prepared a packet that will be mailed to all pediatric audiologists by January, 2016 to remind them of the reporting requirements and send timely referrals to EI.

#### **D. Significant Changes**

In May 2015, Ms. Phatak was hired as the EHDI Specialist and began her new role on May 27<sup>th</sup>, 2015. This position had been vacant since July 2014. Ms. Phatak obtained a Masters of Public Health degree from Des Moines University in 2011 and previously worked as a full-time EHDI follow-up coordinator at the Iowa Department of Public Health from 2010-2015. Having this person devoted full-time to the EHDI program will be critically important to continue improving loss to follow up.

##### Contracts or subcontracts

The ECHO team at Illinois State University executed a project leadership change on July 1<sup>st</sup>, 2015. The principal investigator at ISU changed from Dr. Lindsay Bondurant to Dr. Anthony Joseph. A full review of the training program was conducted to establish a reference point and change indicators. The ISU ECHO team continues to provide hands-on trainings to local health departments and Home Visiting program personnel.

#### **E. Collaboration/Partnerships and Coordination:**

The Illinois EHDI program is a shared legislative mandate; therefore, collaboration is vital to the success of the program. It is the collaboration of three state agencies: The University of Illinois at Chicago- Division of Specialized Care for Children (Title V); Illinois Department of Public Health, and Illinois Department of Human Services- Bureau of Early Intervention (Part C).

The UIC-DSCC helps families arrange, coordinate and pay for the child's specialized medical treatment when the child has an eligible medical condition and certain financial criteria are met. UIC-DSCC provides financial assistance for treatment including otolaryngology examinations to develop a medical treatment plan, audiometric testing for treatment of the hearing loss, hearing aids, supplies and surgical procedures. Once a hearing loss is identified and the referral is made to DSCC, the infant's parents are contacted by DSCC staff to offer assistance with care coordination, and to provide an application to the Institute for Parents of Preschoolers Who are Deaf. Prior approval from DSCC is required for ongoing audiological services and provision of hearing aids for financially eligible families.

IL Department of Public Health is responsible for collecting information on each child with a positive hearing screening result and maintaining a registry of confirmed cases, including information needed for the purposes of follow-up.

Early intervention services in Illinois are administered through the Department of Human Services, Part C (Early Intervention) program. Part C, EI services are available statewide through a network of enrolled providers. EI's mission is to assure that families who have children, birth to three, with diagnosed disabilities, developmental delays or substantial risk of significant delays receive resources and support that assist them in maximizing their child's development, while respecting the diversity of families and communities. EI services include assistive technology, audiology, aural rehabilitation, and developmental therapy, medical services for diagnostic and evaluation purposes, services coordination, and speech and language therapy among others.

### **Other State Collaborative Efforts:**

Illinois Deaf and Hard of Hearing Commission (IDHHC)- IDHHC works to advance the interests of all Illinois citizens with a hearing loss by advocating for systemic improvements, promoting cooperation and coordination among entities serving people who are deaf and hard of hearing and disseminating information to eliminate negative stereotypes surrounding hearing loss.

The Illinois School for the Deaf- State School for the Deaf educates students who are deaf or hard of hearing to be responsible, self-supporting citizens.

Illinois Hands & Voices/Guide By Your Side- In partnership with Illinois EHDI program- GBYS matches families with trained parent guides who also have children with a hearing loss. The parent guides provide unbiased emotional support and resources. GBYS is a program of Illinois Hands & Voices, a non-profit organization dedicated to supporting families that have children who are deaf and hard-of-hearing without a bias towards communication modes or methodologies.

CHOICES for Parents- A statewide coalition of parents and professionals providing access to support, information, and resources to families of children with newly identified hearing loss.

Home visiting programs (IL Early Head Start and the Parents as Teachers) collaborate to provide objective hearing screening for all enrolled children 0-3 years of age. This helps decrease loss to follow-up rates among babies that fail to return to the hospital or an outside facility for an outpatient screen or a diagnostic evaluation upon discharge.

### **F. Monitoring/Data Collection and Analysis**

The coordinated efforts of IDPH, DHS, and DSCC are required to make the program effective in assuring early identification and intervention to meet the needs of infants with hearing loss and their families. Together, all three state agencies track the state's progress towards achieving the national EHDI goals of screening no later than 1 month of age, diagnosis no later than 3 months of age, and enrollment in early intervention no later than 6 months of age. Data was analyzed to determine what factors contributed to infants not receiving follow-up services and the reasons they are moving to loss to follow-up.

Listed below are the projects that took place in year 2015:

- I. Reducing loss to follow-up rates by offering technical assistance to selected hospitals with high (10% or above) refer rates.

In the beginning of July 2015, the EHDI program staff gathered to evaluate the quarterly report cards of all birthing facilities to determine facilities with high refer rates. The team selected ten hospitals that showed a refer rate of 10% or above and decided to conduct a site visit at each of those hospitals starting August 2015. The purpose of the site visits was to: review newborn hearing screening and follow-up procedures; identify strengths and areas for improvements; share best practices on hearing screening and follow-up procedures; and develop a clearer picture of the newborn hearing screening program at the birthing facility and their technical assistance needs. It was designed to help hospitals that are not meeting the national 1-3-6 EHDI goals by performing a thorough review of their protocols and procedures during the site visit. In the year 2015, the EHDI program staff conducted site visits at four different hospitals on 08/10/15; 09/02/15; 11/10/15; 11/12/2015.

Each facility was initially recommended to provide education and training to all new and existing newborn hearing screeners by utilizing the NHSTC online and reviewing the skills competency checklist. In addition, the hospital staff was strongly encouraged to follow best practices on newborn hearing screening and follow-up to help lower their refer rates. These recommendations included:

- Exploring reducing the number of babies referred by screening infants in a quieter environment and posting a sign that states “Quiet! Screening in Progress” to help reduce the noise levels in the nursery.
- Allowing time for the vernix to clear and repeating screening close to hospital discharge if infants do not pass the screen initially.
- Ensuring timely maintenance (calibration, etc.) of the hearing screening equipment.
- Encouraging families to return for follow-up testing if their infants miss or do not pass the initial hearing screening prior to the hospital discharge.

The site visit was followed by a phone meeting to see if there was any assistance needed in implementing the recommendations as listed above. A detailed site visit report was prepared and emailed to the OB manager at each facility to ensure complete understanding of the short and long-term goals discussed during the site visit.

## II. Evaluation of OAE Hearing Screenings at local health departments to monitor progress toward reducing the number of infants loss to follow-up/documentation:

The UIC-DSCC EHDI staff conducted an evaluation in October 2015 to see if any technical assistance was needed or if there were any other questions or concerns. To gather feedback from each department, the EHDI program staff designed a survey to collect information on primary and secondary contacts at each department; the number of children screened to date, and if the results were being reported to the IDPH within 30 days. The survey was emailed to the primary contact at each health department and a meeting by phone was requested to be scheduled in November to discuss the survey responses.

The survey findings indicated the departments had conducted anywhere from 2-40 screens to date with minimal reporting to the IDPH and some departments submitted incomplete reporting forms. During the follow-up meeting by phone, the EHDI staff member provided guidance on how to complete the reporting form and encouraged timely submission. The EHDI staff member also supplied reporting forms via email to those departments that were not aware of the reporting requirements and provided guidance on making timely referrals to pediatricians/pediatric audiologists to ensure timely diagnostic evaluation on those children who do not pass their outpatient hearing screen.

## G. Significant Findings

As of Dec 15<sup>th</sup>, the current data shows in the year 2015 from January-September, there were 1322 infants who did not pass the hearing screening. Of these infants: 208 were documented to have normal hearing; 123 infants were diagnosed with a hearing loss; and 940 infants remain in-process and currently count towards the lost to follow-up numbers. Although the Illinois EHDI program has seen some positive changes in the loss to follow-up numbers in the last three years decreasing from 80.4% in 2013 to 73.1% in 2014 and to 71.1% in 2015 (January-September), there is still an ongoing need to conduct a more in-depth analysis of the factors that contribute to loss to follow-up rates after newborns refer on their newborn hearing screening. The Illinois EHDI program recognizes that the late identification of hearing loss and lack of access to appropriate and timely intervention services

can have life-long negative consequences for infants who are deaf or hard of hearing and their families. To further decrease the loss to follow-up rates, Illinois will continue to develop strategies and work on the quality improvement strategies and implement them statewide if they prove to be successful on a smaller scale. Since Illinois has consistently met the goal of over 98% of infants screened no later than one month of age, the quality improvement efforts will focus more on increasing the number of children receiving diagnostic services no later than 3 months of age and early intervention services no later than 6 months of age.

## **H. Listing of Publications and Other Materials**

- I. Information for Parents (Newborn Hearing Screening General Brochure): This brochure is designed to educate parents on the importance of newborn hearing screening, follow-up process, types of screening and what the screen results mean. This brochure was revised in the summer of 2015 to include information on EHDI-PALS to help families locate a pediatric audiologist within their area that serves children 0-5 years of age. Other changes included updating existing contact numbers for the Bureau of Early Intervention. To make the brochure more culturally sensitive, the EHDI program staff added a new language (Arabic) to accommodate families that only speak this language. Previously, this brochure was only available in English, Spanish, French and Polish.
- II. Next Steps for Newborn Hearing Screening Follow-up: This brochure is designed to educate parents on how to follow-up after their child refers from the newborn hearing screening at the hospital. It also provides information on professionals (e.g. pediatric audiologist, otolaryngologist, etc.) that may work with their baby and outlines their specific roles. One major change that was made to the brochure this year included adding information on cytomegalovirus so parents and providers are aware of the legislation and can prepare accordingly so the infants can be tested for congenital CMV prior to 21 days of life. This brochure is now also available in Arabic in addition to English, Spanish, French and Polish.
- III. Crib Cards: Crib cards were created to be utilized by the hospital staff so they can provide written screening results to the families upon discharge. These cards serve as a reminder to the families that they need to follow-up with the doctor or the audiologist if their child refers from the newborn hearing screening prior to hospital discharge. This year, a couple of changes were made to the crib card including modifying the title on the back of the card to say “A pass is not a pass for life.” It helps remind families of the potential for late onset or progressive hearing loss. Other changes that happened this year included adding the word “guardian” next to mother to include those families that have either legally adopted the child or are taking care of the child in their parent’s absence. Another change that occurred was changing the following statement from testing is needed to testing is “required” to encourage families to do timely follow-up. This card is currently only available in English and Spanish. However, translations are in process to accommodate families that speak other languages such as French, Polish, and Arabic.
- IV. EHDI 3-6 Month Roadmap: Through NICHQ (National Initiative for Children’s Healthcare Quality) participation, the Illinois EHDI program created a roadmap that is focused on 3-6 part of the entire 1-3-6 model. The reason why it was designed that way was because the intent is to distribute this roadmap to the providers who perform follow-up after a child has failed their newborn hearing screen. This roadmap has been finalized and posted to the illinoissoundbeginnings website. It is available in English and Spanish.

## V. Guide By Your Side Educational Materials

- a. Webinars: There were 12 webinars conducted monthly in the year 2015. These are also available on the Illinoissoundbeginnings website. Please see below for the list of topics discussed during those calls:
  - i. 7 Strategies to Enhance the Safety & Success of Your Children; 01/26/15
  - ii. The ABCs of Illinois Service Resource Center; 02/23/15
  - iii. Promoting Literacy Skills for Deaf & Hard of Hearing Children; 03/23/15
  - iv. Social Media- A World of Deaf & Hard of Hearing Resources; 04/28/15
  - v. T-Visits: Distance Therapy for Parents & Their Infants/Toddlers; 05/19/15
  - vi. Literary Resources- There's a New Kit in Town; 06/30/15
  - vii. Cochlear Implants – What's new and more; 09/28/15
  - viii. Phonak Pediatrics: Access to more than just audibility; 10/26/15
  - ix. Unilateral Hearing Loss: Impacts on Language, Social & Emotional Development; 11/23/15

The following conference calls were also arranged to provide information about hearing and hearing loss to Spanish speaking families:

- i. New Diagnosis: Hearing Loss and what is a hearing test battery; 09/22/15
  - ii. New audiology terms & their meaning to help you better understand results & recommendations; 10/13/15
  - iii. Follow up appointments; a live time commitment; 11/10/15
- b. Newsletter: IL E.A.R.S (Events and Resources Statewide) is produced by IL Hands & Voices, Guide By Your Side. It has information for parents and professionals with contents that include events, resources and articles written by various organizations, professionals and families of children with a hearing loss. These following newsletters are available on the Illinoissoundbeginnings website: 02/2015; 08/2015; 11/2015.
  - c. Quarterly Reports: These reports were submitted for each quarter in 2015 except the last quarter that is still in process. These reports highlight program services and events along with data on referrals such as the number of children referred to GBYS; age; ethnicity; primary language; gender; medical history; type of hearing loss and insurance information of enrolled families. These reports are available on the Illinoissoundbeginnings website.
  - d. Family Education & Outreach Days: These days are organized by GBYS guides and designed to bring together families of children with a hearing loss so they can attend a fun event filled with crafts, activities and storytelling while they get an opportunity to meet one another and share their experiences. This two-hour event is offered free of charge and is limited to 30 participants. Sign language interpreters are also available upon request to accommodate families that have a need. These days were held on 01/17/15; 08/05/15; 11/21/15.

- VI. ICAAP- Physician Task Force: In December of 2014, CHOICES for Parents implemented a Physician Task Force; their mission is to increase awareness of early hearing detection and intervention through the 4 C's: Communication and Collaboration with Community partners as well as our partnership with Chapter Champions. The meetings were held on a monthly basis on the following dates: 01/26/15; 02/23/15; 03/30/15; 04/27/15; 05/28/15; 06/25/15;

07/30/15; 08/27/15; 10/15/15. The team gathered to work on a few projects together including a survey for physicians; discussing educational articles to submit for the Illinois Chapter of American Academy of Pediatrics (ICAAP) e-newsletter; an article to introduce the EHDI Chapter Champions that was posted to the Illinoisoundbeginnings website.

The physician survey was designed to gauge the knowledge and comfort level of IL physicians regarding newborn hearing screening and follow up practices. A 10-question survey was created in April of 2015, covering topics such as levels and types of hearing screening taking place in the office, when re-screening and referrals happen, awareness of local pediatric audiology services, reporting practices, and comfort levels in counseling families dealing with hearing loss. As of December 15<sup>th</sup>, only ten responses have been received. The survey remains open at this time in hopes to gather more responses. Based on the responses received once the survey is closed in the near future, the team will then determine the areas that need attention, and how to best provide that support, such as via articles, webinars, trainings, etc. The team hopes to develop educational materials and provide support to physicians that will help raise awareness and reduce loss to follow up rates in Illinois. Currently, there are no regulations to mandate any screenings between discharge from the hospital at birth and entering school. The primary responsibility falls on the primary care provider/medical home of the child. However, as a low incidence disability, hearing loss can be overlooked, creating compounding issues related to language, social, emotional, and academic development.

- VII. UIC-DSCC and CHOICES for Parents hosted a booth at the annual Fall ABC (Autism, Behavior, and Complex Medical Needs) Conference in Palos Hills, IL. There were 220 registrants; participants included parents and a variety of professionals such as physicians, developmental therapists, social workers, nurses, and EI providers. Information was provided about UIC-DSCC services including care coordination, financial assistance based on income and medical eligibility and; CHOICES for Parents as a central starting point for parents for information, advocacy, support, and referral for families of children with hearing loss. Many people were unaware of these services and were glad to learn and take information back with them to share with their colleagues and families that they serve.

## **I. SUSTAINABILITY**

Based on the positive feedback received from the professionals and families served over the years, it is believed that Illinois EHDI program makes a significance difference in the lives of many deaf and hard-of-hearing children and their families. Illinois EHDI program is an unfunded state mandate; sustainability without a direct state funding source proportionate to the size of the state remains an obstacle. The loss of federal funding would have a major impact on the existence of the EHDI program from the administrative home at the state level to individual hospital screening departments, diagnostic audiology services, and EI providers. All birthing facilities in the state are currently screening infants at a rate of 98% or above. The EHDI program anticipates that the screening rate may be sustainable to some degree, however, without HRSA funds, the hospital personnel will no longer have the support from the EHDI team professionals to provide an oversight of their newborn hearing screening program; technical assistance; guidance on education and training needs; and strategies to reduce the number of infants lost to follow-up upon discharge. This could result in hospital personnel not following best practices on newborn hearing screening and follow-up and could further increase the number of infants that move to lost to follow-up in Illinois. In order to provide limited support to hospitals and families of children with a hearing loss, the state EHDI program may need to explore funding from other



public health projects and consider revenues from other sources to support the program activities. Currently, all facilities with screening equipment and audiologists administering diagnostic evaluations report into the statewide database (Hi-Track) that is supported by the funds provided by the Center for Disease Control and Prevention.

The goals of the HRSA grant are designed to help develop strategies to reduce the number of infants lost to follow up at all stages of the early hearing detection and intervention system. With the help of HRSA funds, our program has implemented some additional small tests of change in this past year that have proven to be successful and can be spread across the state. With the statewide implementation of some of those strategies and ongoing promotion of best practices through technical assistance, we anticipate that these efforts will help make this program more sustainable. However, Illinois EHDI program is making every effort with constant hard work to maintain and maximize federal funding sources so we can continue to provide the best quality of care to serve the needs of the children and families of Illinois.