

Iowa EHDI News

Your Sound Source for Early Hearing Detection & Intervention Information

Summer 2015

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Importing Data

Consider joining your peers across Iowa in importing demographics and hearing screening results into eSP™. Importing the demographic data not only decreases the amount of staff time for manual entry, but also decreases duplication (manual entry into multiple data systems), avoids missing children, and decreases the potential for errors in spelling or results entry.

eSP™ interfaces with hospital data registries (e.g., admitting or electronic health records) to import data from the hospital's database into eSP™. This involves the creation of an ASCII file that contains patient information including demographics, contact information, race/ethnicity and risk factors. One field that will still need to be entered at this time is the PCP/medical home. No software is needed to enable you to do the import. The EHDI program will provide instructions and the data dictionary needed to create the file so the information can be passed along to hospital information technology (IT) personnel. Once the file is created, the EHDI database vendor, OZ Systems, will test the file to ensure it works correctly and then the EHDI staff in collaboration with OZ will schedule a WebEx conference to walk you through the steps to set up the import.

If you are interested in learning more about importing, please contact Tammy O'Hollearn at tammy.ohollearn@idph.iowa.gov or by phone at (515) 242-5639. If you set up the system to import demographics, you can also set it up to import newborn hearing screening results too from most pieces of hearing screening equipment. Join your peers and save time by setting up an import file today!



Iowa's Early Hearing Detection & Intervention Program

Sound Bites

Updates from the EHDI Advisory Committee Meeting on July 9, 2015.

MEETING SUMMARY

- Hearing Aid and Audiological Services Funding Update: Starting July 1, 2015 a total of \$162,000 was appropriated for FY 2015-2016 for hearing aid for Hearing Aid and Audio Funding. There are approximately 30 children on the waitlist that will be processed first. Please encourage parents to send in their applications soon.
- The EHDI program is looking into texting for follow-up purposes. A small number of states have begun texting families and have had some success. Options are currently being explored.
- A primary care provider mailing has gone out with a letter and educational information. It went out to roughly 1,900 primary care providers throughout the state. Another mailing went out to midwives across the state including information about the number of out of hospital births, parent refusals, and number of children lost to follow up. It also highlighted trends and improvements of screening for out of hospital births.
- There was a pilot tele-audiology program done between CHSC clinic in Oelwein and Lenore Holte from University of Iowa. Holte performed remote ABR assessments for the CHSC clinic using video and operation capabilities. Though underutilized, the program worked well when assessments were performed. The EHDI program is currently piloting the use of diagnostic equipment in the NW AEA. The pilot may expand to other AEAs that have expressed interest.
- The Advisory Committee reviewed the EA referral form. This form is now available online.
- EHDI team will review current scripts for screening staff to use when communicating results to the parents of an infant. The EHDI program will send out the scripts again to the birthing facilities and also make them available on the website.
- Various outreach strategies were discussed. One included connecting with OB clinics to hand out hearing screening brochures at prenatal appointments. The group also discussed generating videos for the clinics. Additionally, edits to the newborn hearing screening brochure. Finally, scripts for nurses to use when talking to the parents about the results of the hearing screen were discussed.
- EHDI is in the process of partnering with WIC in an attempt to decrease the numbers of infants lost to follow up/documentation. Approximately 45% of all children LTF/D also receive WIC services. The purpose of partnering is so WIC nurses may assist with scheduling a follow up screen while completing an initial needs assessment for the family.
- EHDI and Dried Blood Spot Screen are working on building an integrated database which is expected to roll out in fall 2016.
- The Advisory Committee began to work through an EHDI self-assessment to prioritize program goals.

Advisory Committee Members

Stephanie Childers

Educational Audiologist/Leadership Committee

John Cool

Assistant Administrator
Iowa School for the Deaf

Jill Filitano Avery

Iowa Department of Human Rights
Office of Deaf Services

Marhsa Gunderson

Audiology Consultant
Deaf & Hard-of-Hearing
Iowa Department of Education

Diana Hanson

Pediatric Audiologist
Iowa Ear Center

Teresa Hobbs

Early ACCESS Regional Coordinator
Northwest AES 12

Jeffrey Hoffman

Iowa Academy of Family Physicians

Sabrina Johnson

Medicaid Policy Specialist

Marcus Johnson-Miller

Title V Director
Iowa Department of Public Health

Sarah Johnston

Parent Representative

Kelsey Maginity

Prevention and Victim Service Advocate
Deaf Iowans Against Abuse

Kathy Miller

Iowa Association of the Deaf

Kimberly Noble Piper

State Genetics Coordinator
Iowa Department of Public Health

Michelle Simmons

Birthing Facility Representative

Mary Stevens

Director of Special Education
AEA 267

Chalis Treloar

Audiologist for ENT office

Linda True

Educational Audiologist

Michelle Vacarro

Parent Representative

*EHDI program staff and the audiology technical assistance team are also advisory committee members. (See page 5 for their contact information)

Next EHDI Advisory Committee Meeting: October 1, 2015

Comments or questions?

Contact Tammy O'Hollearn at tammy.ohollearn@idph.iowa.gov or at either (515) 242-5639 or (800) 383-3826 (toll free).

A Look at Sedation and ABR

By: Lenore Holte, Ph.D., CCC-A

Several state EHDI programs, including the Iowa EHDI program, have been receiving questions and concerns from parents and practitioners regarding the use of sedation in infant pediatric diagnostic Auditory Brainstem Response (ABR) testing. In order to get a quiet enough recording to estimate a baby's hearing thresholds, the baby needs to be sleeping or just very quiet and still. The use of chloral hydrate sedation in medical offices used to be routine in ABR, but this is no longer consistent with current recommended Guidelines for Pediatric Sedation (<http://pediatrics.aappublications.org/content/118/6/2587.full.pdf+html>).

Most pediatric audiologists in the United States are making the effort to complete ABR testing under natural sleep with no sedation if a baby is young enough. In most clinics in Iowa, if a baby is tested before 6 months of age, it can usually be done without sedation. Iowa has a very limited number of pediatric audiologists who do ABR testing so timely referral is essential to ensure an early diagnosis. This will help the Iowa EHDI system reach our goal of diagnosis of congenital hearing loss by 3 months of age. In the rare instances when sedation is necessary on an older child, the guideline requires it be performed in the operating room under general anesthesia, under the supervision of an anesthesiologist or nurse anesthetist. This is one more reason it is essential to get the baby into audiology as soon as possible after referring on a newborn hearing screen and rescreen, so unnecessary sedation is not warranted. Repeated rescreens should be avoided, because this can just prolong the age at which the baby gets the diagnostic ABR test and can increase the likelihood sedation or anesthesia will be necessary. An added advantage of following up quickly is the optimization of speech and language skills that early diagnosis and intervention provide.

The Iowa EHDI staff are available to answer any questions about this or to provide information about audiologists in Iowa who will do unsedated ABRs on small infants. If you have any questions about this, contact Lenore Holte (lenore-holte@uiowa.edu) or Emily Andrews (emily-andrews@uiowa.edu).

Special highlight:

Northwest Area Education Agency has teamed up with the University of Iowa and the EHDI program to pilot Auditory Brainstem Response testing in the Siouxland Area. Infants who do not pass the screening at birth and need more diagnostic testing are now able to have ABR testing done closer to home. Results will be read by the University of Iowa staff and a NW AEA audiologist will be able to discuss the results with the parents. ABR measures are used to predict hearing sensitivity and assess the integrity of the 8th cranial nerve and the auditory brainstem structures.

Welcome Kristy!

Kristy Johnson recently joined the EHDI team as the EHDI Follow up and Family Support Coordinator. She recently graduated from the University of Northern Iowa with her Masters in Social Work: Social Administration. Prior to graduation, she worked for 7 years as a direct care staff and program coordinator serving those with differing abilities. We are happy to welcome Kristy onto the EHDI team!



We want to hear from you.

We value your feedback and are here to answer any questions you may encounter throughout the hearing screening and follow-up process. Below is contact information for our dedicated staff. We look forward to hearing from you.

State EHDI Coordinator

Tammy O'Hollearn
Iowa Department of Public Health
(515) 242-5639 - direct
tammy.ohollearn@idph.iowa.gov

EHDI Follow-Up/Family Support Coordinator

Shalome Lynch
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shalome.lynch@idph.iowa.gov

EHDI Follow-up/Family Support Coordinator

Kristy Johnson
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kristy.johnson@idph.iowa.gov

EHDI Program Assistant

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EHDI Intern

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Audiology Technical Assistance

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University of Iowa Hospitals and Clinics
Center for Disabilities and Development
(319) 384-6894
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Center for Disabilities and Development
(515) 450-1132
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Be watching for a web update!

The IDPH website is currently undergoing a redesign. The EHDI team has been working hard to make sure that it is easy for you to navigate and full of helpful resources. As it rolls out, please let us know if you have any questions or need assistance with finding something. The roll-out should be taking place mid-October.

EHDI Toll Free Number: (800) 383-3826



New brochures: The EHDI program has recently partnered with the rest of the newborn screening programs to create a joint brochure which will replace the current EHDI brochure for parents. The brochure will give parents a comprehensive guide to newborn screening and reduce the number of materials distributed. The joint brochure should be available by January 2016. The joint brochure will be available at that time to order by calling 1-800-369-2229. Look for more correspondence about the brochure from the newborn screening programs in the coming months.

The reinstatement of Quarterly Reports

As many have noticed, the EHDI program began sending out quarterly quality assurance reports again this year in order to help birthing facilities track their progress as it relates to state goals. The reports are meant as a snapshot in time to determine if birthing facilities are meeting state and national goals, state law and best practices. They are run two to three weeks after the quarter is done. The quarters are defined as January to March, April to June, July to September and October to December. The reports have been a great tool for the EHDI program to ensure birthing facilities know how well they are doing and where there is room for improvement. The EHDI program appreciates everyone who has taken the time to look over their reports and make systemic changes based on those reports. A few notes regarding the reports:

- Timely entering of data is very important. Since the report is a snapshot, if results have not been entered into the system two weeks after the end of the quarter, the data will not be included in the report. Since the law states that demographics and screens must be entered within six days of birth, all data should be entered by the time the EHDI program runs the report. The exception for entering screen results is for NICU babies, however, demographics and the infants primary care provider, as well as any applicable risk factors should be included.
- There are a number of birthing facilities who are not entering the outpatient test location correctly. In order for the screen to be counted in the outpatient screens, both the test location and the test type need to be labeled as outpatient. Some birthing facilities are letting the system default to the location they set for entering inpatient screens. If you have defaults set, please ensure you change the test location to outpatient and select your facility and test type to outpatient screen when entering the results.
- Data is a good indicator, but does not tell the whole story. Discrepancies can arise for a variety of reasons including data entry errors, small volumes, etc. It is important that your team review the report and the data in the system. If there are mistakes that can be corrected by your token users, please have them make the changes and if it is related to screening results, contact the EHDI program for assistance. If you know that something is not right, but you are not sure how to look up the information in the system or you are not sure how to correct the error, please contact the EHDI program for assistance.
- Remember, the reports are a tool for screening programs to use to determine progress in meeting state and national goals. It is important for the birthing facilities to take ownership of the data and implement quality improvement processes, as needed on the clinical side or data entry side. Other states found great success with state report cards being used to affect change and so far, Iowa has had the same experience!

We appreciate your continued feedback on ways that we can make the reports even better. It has been helpful to hear what birthing facilities find confusing or beneficial. Learning how to run your own reports will allow you and your team to take your own data “snapshots” and troubleshoot at any point in time. A preliminary webinar took place on September 30, 2015. If you would like a copy of the webinar or are interested in learning how to run your own reports, please contact Emily Sadecki at emily.sadecki@idph.iowa.gov.

EHDI Measure Adopted by the Joint Commission

* *The 2016 Flexible Reporting Options can be accessed from The Joint Commission website posted under the “Measurement” section, ORYX Performance Measurement Reporting at http://www.jointcommission.org/performance_measurement.aspx.*

Beginning in January 2016, the Joint Commission will begin to evaluate electronic specifications of a Clinical Quality Measures (eCQM) for Early Hearing and Detection programs. The measure set that covers EHDI is: eCQM EHDI-1a & CMS #31 & NQF #1354: “Hearing Screening Prior to Hospital Discharge”. This measure evaluates the number of live births that have received a hearing screen prior to hospital discharge.

As many of you know, Iowa is transitioning to a new integrated newborn screening information system. As part of the new system, interoperability tools will be available to help facilitate the electronic transfer of information from Electronic Health Records and hearing screening devices. The Newborn Admission Notification Tool, NANI, is a tool that can facilitate the electronic transfer of birth records to the state EHDI program using ADT messages. OZ Telepathy™ for EHDI, can electronically transfer hearing screening results directly from the device to the state EHDI system. Both of these tools will help hospitals ensure they are meeting the eCQM for EHDI, ensuring all births and hearing screenings are recorded electronically. For more information on the new system or purchasing these tools for your facility, please contact Kim Piper at Kimberly.piper@idph.iowa.gov or phone (515) 720-4925.

Hospital Showcase: The Good & The Bad

A hospital in SW Iowa was able to facilitate the diagnosis of an infant by one month of age. The infant was brought back to the hospital for an OP screen within one week of birth and did not pass. The hospital immediately referred the child for a diagnostic assessment and was diagnosed with a hearing loss two weeks later! In another example, a child was transferred from provider to provider rather than being moved onto a diagnostic assessment after the infant failed on the outpatient hearing screen. This resulted in the diagnosis not taking place until a year and a half after the child's birth. Keep these stories in mind as examples of what to do and what to avoid!

Midwives & Newborn Screening

Improving care for Iowa babies born outside the hospital

Midwives play a critical role in identifying hearing loss in babies that are born out of the hospital (OOH). They are the first person to communicate the importance of the newborn hearing screen to the baby's family and help the families connect with proper resources, such as screening providers. While midwives are so important to early hearing diagnosis and intervention, there has historically been a communication gap between the Iowa EHDI program and midwives. This may be for a number of reasons, including variation in individual health care practices and provider attitudes and knowledge about newborn hearing screening. In the past few years, there

have been tremendous improvements in the hearing screening outcomes for babies born out of the hospital as Iowa EHDI and the midwife community have increased collaboration and communication. Together, we can ensure that no matter where a child is born in Iowa they have access to timely hearing screening services.

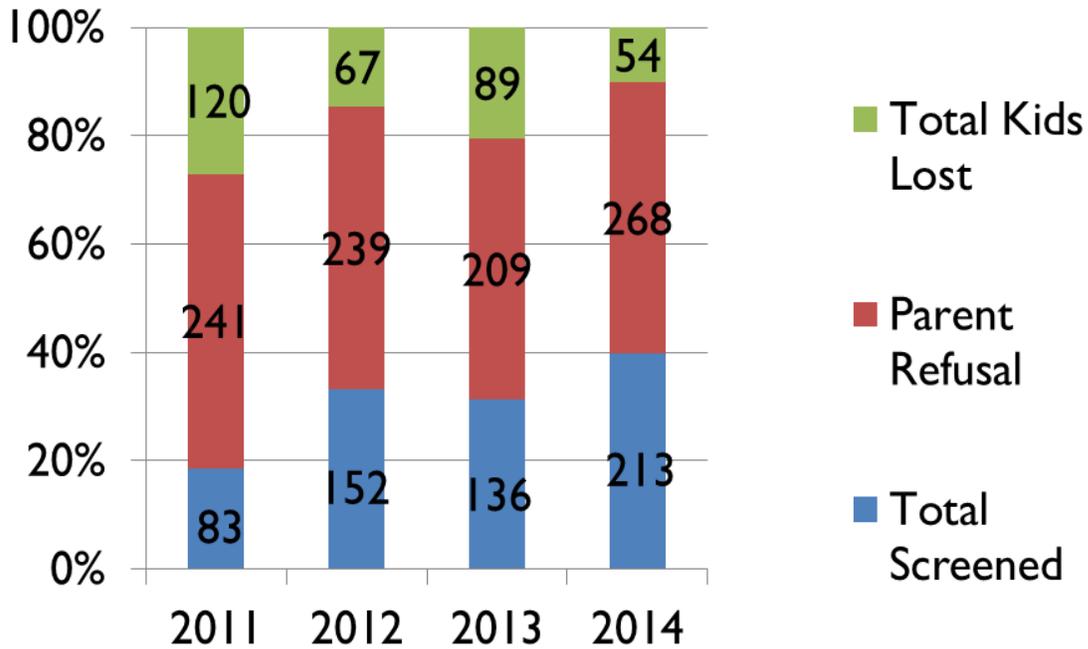
In an effort to enhance understanding of newborn hearing screening and timely follow-up, Iowa EHDI program recently distributed a packet to Iowa midwives. The packet contained educational materials including a two page letter stressing the importance of newborn hearing screening; current data & statistics on hearing loss; a poster about newborn hearing screening; hearing screening misconceptions vs. clinical facts; and a letter from the mom of an infant born out of hospital whose child was diagnosed with permanent hearing loss.

Table I below shows a comparison between the total number of children screened; the number of children moved to lost to follow-up/documentation and; the number of refusals received by the Iowa Department of Public Health EHDI program from 2011 to 2014. Iowa EHDI noticed a drastic improvement in the overall numbers of infants born outside of the hospital that are receiving hearing screens. The data also shows a decrease in the numbers of OOH births being lost to follow up/documentation related to ongoing quality assurance activities and education. The total number of refusals has remained consistent at approximately 48%.

The number of OOH children that were lost to follow-up/documentation decreased from 27% in 2011 to 10% in 2014. To bring a positive change in the numbers, Iowa EHDI program has worked hard and utilized some powerful follow-up strategies. This has included calling parents and primary care providers for whom the demographic data was available, including hearing screening information in home-birth packets, as well as mailing information about newborn hearing screening to parents of infants recently born. The information encourages the parents to get their



Table 1. Out of Hospital Births Data 2011-2014



infant screened and includes the number to Iowa Family Support Network who can assist the family in locating a provider near their home.

Although Iowa EHDI program has seen recent success in the numbers, OOH births still make up about one-fourth of all children lost to follow-up/documentation statewide. In the coming months, Iowa EHDI will continue its efforts to better understand the needs of babies who are born outside of the hospital. Some of the future strategies to eliminate barriers will include: increased outreach to midwives to improve screening rates; continued parent education; continued follow-up activities with OOH families; and providing support to midwives if they decide to conduct hearing screening on infants they assist in the birthing process. No matter where a baby is born in Iowa, the collaboration between the Iowa EHDI program and providers of all types will ensure that they have the hearing screening services they deserve.



Thank you.



Iowa's Early Hearing Detection & Intervention Program

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