

Iowa EHDI News

Your Sound Source for Early Hearing Detection & Intervention Information

Summer 2016

The EHDI World

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Almost two-thirds (or over 75% of babies born in the state) of all birthing facilities in Iowa are now importing or using NANI to import demographics into the INSIS database for newborn hearing screening. In the last quarter, several birthing facilities completed the process of moving away from manual entry and are currently in the process of moving nine facilities to importing or NANI. The EHDI team has been busy sending birthing facilities information to set up the import and working with facilities IT to answer questions as they come up in development. As a reminder, 100% of Iowa's birthing facilities will be expected to move to either importing (flat file) or NANI (HL7 messaging) by December 31, 2016! We encourage you to start the discussion with your IT on the best option for your facility as soon as possible.

Results from Sara Lincoln at NW AEA re.ABR pilot:

A pilot for Auditory Brainstem Response (ABR) diagnostic testing began in September 2015 at the Northwest Area Education Agency (AEA). This pilot started as there was an identified need for more ABR providers through the state, particularly in areas with higher lost to follow up/documentation rates, for children to receive diagnostic testing after referring at their outpatient hearing screen.

EHDI audiology TA's at the Center for Disabilities and Development at the University of Iowa worked together with the Northwest AEA audiologist to complete training on ABR testing. ABR equipment was placed at the Sioux City office and the Northwest AEA audiologist received support through online communication from the TA audiologists.

KUDOS...!

to to St. Luke's Cedar Rapids, Mercy Cedar Rapids, UnityPoint Health Des Moines and Mercy Des Moines on moving quickly to implement NANI (HL7 messaging) in their respective facilities. Our INSIS vendor is working with them on development and testing and they should be ready for implementation soon!



The ABR machine was unavailable because of needed repairs mid-December 2015 through April 2016. During the 7 months the ABR machine was functioning, there was a total of 15 ABR tests completed with 2 children being identified with a hearing loss.

Prairie Lakes AEA will soon start to pilot ABR testing in their area. There has been strong interest in starting this pilot and training will be scheduled this fall. Stay tuned for more information!

Farewell to Emily Sadecki!

Emily worked with the EHDI program as an intern for a year on a variety of tasks during her time with the program including the redesign of the EHDI program website. She developed one brochure that included information about all newborn screening programs so that families receive one brochure rather than three different brochures. Emily revised quarterly quality assurance hospital reports so they are brief, easy to read and understand. She created a template that links data from numerous reports from the EHDI data system so that 79 reports did not need created individually. Emily completed some data analysis during her time with the EHDI program, created a directory of follow up providers and also helped the program resume the development and dissemination of quarterly EHDI newsletters. On a more personal level, Emily reached out to providers to ensure infants were referred to early intervention and received hearing aids, as needed following a diagnosis of hearing loss.

Emily's work was always prepared on time, and she stood out for her eagerness to engage in the process of learning and discovery within this program. Simply put, Emily was a pleasure to work with during her time with the program. Emily will be missed by program staff. We wish Emily the best in her future adventures!

Hospital Showcase

Showcase 1:

The child referred bilaterally at the birth hospital. He was then referred to the local AEA for follow up. At the AEA, he also referred bilaterally and was referred for ABR testing. He was scheduled for ABR testing prior to 3 months of age. He was found to have bilateral hearing loss. EHDI followed up with the AEA to ensure that the appointment for ABR had been scheduled but besides that the system of care for this child transitioned smoothly from one provider to another.

Showcase 2:

This child referred bilaterally at the birth hospital. EHDI followed up with mom as child referred bilaterally at the OP screen and had nothing scheduled for diagnostic testing. Mom explained frustration with the follow up for her child as she was told she would receive a call to schedule the OP screen from the hospital and didn't. After the family came back for OP screen and her child referred, mom was given information to go to the AEA. When mom called the AEA, she was told her child could not be tested there due to the child being previously tested by AABR. The mom then got information from the AEA of where to go for ABR testing. Mom followed up with her child's primary provider about a referral for ABR testing and she was told her provider had not received a copy of the results of the newborn or outpatient screens. This child has now been scheduled for ABR testing at a diagnostic provider prior to three months of age but not without a lot of frustration and persistence by mom. This could have easily become a child lost to follow up if mom had not kept at it. Please assist families in getting to the next step in the follow up process.

CMV Legislation

Center for Congenital and Inherited Disorders staff are attending a conference in September to learn more information about congenital cytomegalovirus (CMV) infection and testing in newborns.

About one out of every 150 babies are born with congenital CMV infection. However, only about one in five babies with congenital CMV infection will be sick from the virus or will have long-term health problems. Most babies with congenital CMV infection never show signs or have health problems. However, some babies may have health problems that are apparent at birth or may develop later during infancy or childhood. These problems may include:

- Hearing loss - some babies without signs of congenital CMV infection at birth may have hearing loss. Hearing loss may be present at birth or may develop later in babies who passed their newborn hearing test.
- Vision loss
- Intellectual disability
- Small head size
- Lack of coordination
- Weakness or problems using muscles
- Seizures

Congenital CMV infection can be diagnosed by testing a newborn baby's saliva, urine, or blood. Specimens must be collected for testing within two to three weeks after the baby is born in order to confirm a diagnosis of congenital CMV infection.

Treatment includes medicines, called antivirals that may decrease the risk of health problems and hearing loss in some infected babies who show signs of congenital CMV infection at birth. There is currently no FDA approved treatment for CMV. There is a doctor in nearby Minnesota that has treated some babies in utero with good results.

Tammy and Kim are working to develop policies and procedures that best meet the needs of Iowa's newborns; in order to ensure optimal health for those babies with potential congenital CMV infection at greater risk for health problems, and to minimize the interventions of the majority of babies with low risk.

IMPORTANT CONFERENCES ATTENDED:

Cytomegalovirus (CMV) Public Health & Policy Conference – September 25-27

Reminders*

Loaner Equipment

Don't miss screening an infant because of broken equipment. If you are having problems with your hearing screening equipment, the EHDI program has a limited number of loaner screening OAE units available for hospitals to use while their screening equipment is being repaired. The EHDI program also has an AABR unit available for loan. There is no charge for borrowing the equipment, other than using your own consumables for screening and the cost of shipment back to the EHDI program when you are done using the equipment.

For information about loaner units, please contact:

Hearing Equipment Coordinator.....(800) 272-7713

--Or--

EHDI Audiology TA

Lenore Holte (Lead Pediatric Audiologist).....(319) 356-1168

Emily Andrews (providing support to the eastern half of Iowa).....(319) 384-6894

Bill Helms (providing support to the western half of Iowa).....(515) 450-1132

Equipment Calibration

Did you know your equipment needs to be calibrated regularly? Not only does the equipment need to be inspected by your Biomedical department, it also needs to be checked to see if it is still operating within specific specifications so that it accurately measures what it is designed to measure. Depending on your particular equipment, calibration can be done on-site by a certified hearing equipment technician who comes to your facility, or the equipment is shipped to the manufacturer to be calibrated.

Not sure whether your equipment has been calibrated recently? Check for a sticker with "Date Calibrated" and/or "Date Calibration Due." Most equipment needs to be calibrated annually unless the manufacturer specifies otherwise.

For information about calibration, please contact:

MSR Northwest (800-950-3277) for most OAE equipment and Biologic AABR.

Natus Medical (800-303-0306) for Algo AABR and Echoscreen OAE.

Unsure who to contact?

Email EHDI staff to connect you to the appropriate people.

Texting with Families

Texting with families for follow up is in full force. The EHDI Follow up Coordinators reach out to families via text for children that are still in need of a hearing screen or diagnostic assessment. Please ensure you capture the cell phone number for each family that has one in the INSIS database. We will provide an update on the texting pilot in the next newsletter!

Early Intervention Referrals

Referrals for Early Intervention (Early ACCESS) are now able to be made through INSIS. Children diagnosed with hearing loss (regardless of type or degree) are eligible for Early ACCESS Services. If a referral was made and the family declined services, please note this in the child's record in INSIS.

Video on Newborn Hearing Screening

A short video has been developed for parents to introduce them to newborn hearing screening and the importance of follow up. The video is about two and a half minutes long and it's a perfect educational tool for parents. The video link is available on the EHDI website.

<http://www.idph.iowa.gov/ehdi/families>

Announcements

Hearing Aids and Audiological Services Funding

The Iowa Department of Public Health is pleased to announce the availability of funds for children in need of hearing aids and/or audiological services. Funding was made possible through an appropriation by the Legislature during the last legislative session (2016). Funds are limited – therefore claims will be processed on a first come, first serve basis and considered as payer of last resort. Over 70 children have been enrolled in this program since July 1st. Claims will be accepted for services July 1, 2016 through June 1, 2017 or until the funds run out. If you know of a child in need of hearing aids or audiological services, please have the family contact Provider Claim Systems at (800) 547-6789 for an application or visit <http://www.idph.iowa.gov/ehdi/funding>.

Coming up!

EHDI staff recently sent out two surveys and will be sharing results in the next newsletter. The first survey was sent to audiologists in the state to gather feedback on a hearing loss checklist distributed last fall to assess their experience to date. The second survey was sent to childbirth educators at hospital settings to gather their knowledge and current practices with newborn screening education. Stay tuned for these results!

EHDI staff also sent out postcards to out of hospital birth families and midwives in the state asking for their participation in a work group to explore attitudes, beliefs and barriers that may impact out of hospital birth screening rates. We have received interest from several parents and midwives across Iowa and will soon organize the work group. Stay tuned for information on this work group!

WIC pilot update (last winter 2015)

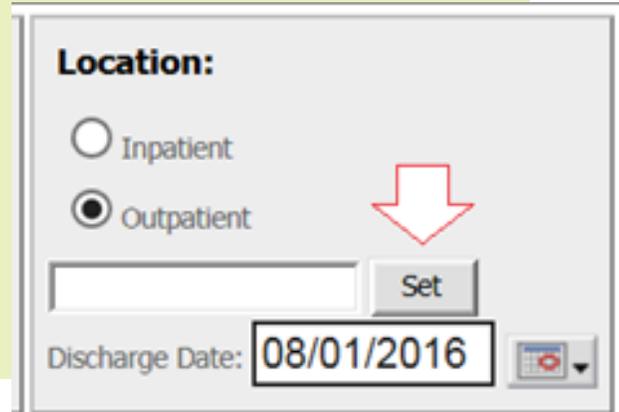
EHDI staff continue to work with local WIC agencies for children in need of hearing rescreens. EHDI is now up to five pilot clinics and sends referrals biweekly. The pilot WIC agencies work with families attending their clinics to assist in scheduling a follow up hearing screen for their children. EHDI and WIC will assess the pilot later this year to determine if this partnership decreases the numbers of children lost to follow up/documentation and improves timely follow up.

Quality Improvement Corner

A work group from the EHDI Advisory Committee has been working on the development of a parent welcome guide. The work group is made of parents, audiologists and EHDI staff and have been meeting since June on this project. The guide is being developed to be mailed or emailed to families of children newly diagnosed with hearing loss within 10 days of the report of hearing loss. The guide will include information, support and encouragement and its main goal is to provide parents with next steps after their child's diagnosis. The guide is in its final stage of development and will be reviewed at the next EHDI Advisory Committee meeting.

BEST PRACTICES TIP

After all necessary information has been entered into a child's record in INSIS and the child has been transferred or discharged, remember to move the child's record to outpatient. You can do this by selecting "outpatient" as the location, entering a discharge date and clicking on "set". EHDI staff has seen an increase amount of records not being moved to outpatient.



Location:

Inpatient

Outpatient

Discharge Date:

Sound Bites

Updates from the EHDI Advisory Committee Meeting

~ EA Service Delivery – Coaching

- State Systemic Improvement Plan – 6 year plan to improve outcomes for child with differing abilities and their families by increasing Early ACCESS services.
- The goal is to individualize services for child in natural settings and demonstrate improved functional outcomes.
- Personal Development Implementation Strategies – Incorporate implementation science in order to develop the capacity to make effective, statewide, and sustained use of evidence based practices.
- Utilizing parent surveys, self-assessments, and data to assess effectiveness of new system.

~ Bill Helms (audiology TA) is completing trainings with hospitals to decrease refer rates and train new nurses.

~ Northwest AEA will be looking for potential grants to obtain their own equipment funding to sustain the ABR pilot program.

~ EHDI has purchased a diagnostic unit to train a Prairie Lakes AEA audiologist to participate in an ABR pilot in that region.

~ Twenty six children on the Hearing Aid and Audiological Services Funding wait list will receive information to begin the hearing aid application process as the legislative session approved the same amount of funding for the next fiscal year.

~ Senator Peterson is looking at proposed legislation for next legislative session on CMV screening for babies in Iowa.

With the introduction of the Universal Newborn Hearing Screening initiative, the number of individuals identified with hearing loss at birth has greatly increased. In order to effectively facilitate early intervention and advocacy from families, audiologists must be equipped with the appropriate counseling skills when informing parents of their child's hearing loss. A review of the literature has revealed several suggestions for informing caregivers of their child's hearing loss. The following suggestions represent the main themes found throughout the literature:

1. Ensure the environment is private and free of distractions.
2. Allow ample time for the appointment.
3. Inform caregivers of the nature of the news (i.e. "This may be difficult for you to hear.")
4. Assess the caregiver's reaction and respond with empathy.
5. Pause frequently to allow the caregiver to express emotion.
6. Validate the caregiver's reaction to the news (i.e. "I understand why you might feel this way.")
7. Ask questions to facilitate discussion. Allow the caregiver to lead the discussion.
8. Provide the caregiver with a brief summary at the end of the appointment, and provide the caregiver with materials to take home (i.e. websites, written materials, DVDs, etc.)
9. Schedule a follow-up appointment to further discuss the diagnosis, but allow the caregiver time to come to the point of acceptance.
10. Review the information at the follow-up appointment.

Counseling is a necessary skill for audiologists which should be included in educational programs. To assess the amount and type of education audiology programs are providing to current students, surveys were sent to all accredited Au. D. programs. Results revealed that all responding programs are providing some form of counseling education, with over half of the responding programs providing seven or more hours of education. This shows a drastic improvement from 1997 data, revealing that only 18% of audiology students received any counseling education⁸. The majority of training is in the form of didactic instruction or discussion, with fewer programs using interactive methods such as simulated patients and role playing. Psychological research reveals that the learning process requires active experimentation, which can only be accomplished through interactive education⁹. Thus, further emphasis on interactive counseling education using simulated patients and role playing is recommended.

1. American Speech-Language-Hearing Association. (2008). Guidelines for audiologists providing informational and adjustment counseling to families of infants and young children with hearing loss birth to 5 years of age [Guidelines]. Available from www.asha.org/policy.
2. National Institutes of Health (1993). Early identification of hearing impairment in infants and young children. NIH Consensus Development Conference Statement. Retrieved from <http://consensus.nih.gov/1993/1993HearingInfantsChildren092.html>
3. White, K. (2008). Newborn hearing screening. *Pediatric Audiology: Diagnosis, Technology, and Management*. Editors Madell and Flexer. Thieme Publications, 31-41.
4. Buckman, R. A. (2005). Breaking bad news: The S-P-I-K-E-S strategy. *Community Oncol*, 2(2), 138-142.
5. English, K., Kooper, R., & Bratt, G. (2004). Informing parents of their child's hearing loss: Breaking bad news guidelines for audiologists. *Audiol Today*, 16(2), 10-12.
6. Luterma, D. (2006, March 21). The counseling relationship. *The ASHA Leader*, 31-33.
7. Margolis, R. (2004). What do your patients remember?. *Hear J*, (6), 10-17.
8. Crandell, C. C. (1997). An update on counseling instruction with audiology programs. *J Acad Rehabil Audiol*, 15, 77-86.
9. Kolb, D. A., & Fry, R. E. (1974). Toward an applied theory of experiential learning. MIT Alfred P. Sloan School of Management.

Ordering Brochures:

To order the Iowa Newborn Screening Program shared brochure for EHDI, Newborn Dried Blood Spot and Critical Congenital Heart Disease, contact the Iowa Healthy Families line at (800) 369-2229. Request publication IDPH131 when calling. NEW- The brochure is now available in Spanish. To request the Spanish version of the brochure, request publication IDPH 131S.

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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(515) 725-2160 - direct
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