Iowa
EHDI News

EHDI
Iowa's Early Hearing
Detection & Intervention System

Your **Sound Source** for Early Hearing Detection & Intervention Information Summer 2009

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National Initiative for Children's Healthcare Quality

The Iowa EHDI program is participating in a learning collaborative through the National Initiative for Children's Healthcare Quality (NICHQ). The goal of the learning collaborative is to test, evaluate and implement changes that will reduce the number of children lost to follow up. States participating in previous years have lowered loss to follow-up rates through the following strategies:

- Making appointments for rescreens prior to hospital discharge
- Obtaining a second point of contact for families
- Verifying the name of the physician that will follow the baby after discharge

The EHDI program is working with hospital, audiology, AEA and parent partners to find ways to improve follow up for Iowa babies. More information to come about this initiative and Iowa's effort to reduce loss to follow-rates.

Advisory Update

The next meeting of the Iowa Early Hearing Detection and Intervention Committee is:

October 1, 2009

10 a.m. - 3 p.m., Location: Iowa Altoona Public Library

October

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Past meeting agendas, minutes and a list of committee members are available online! Visit www.idph.state.ia.us/iaehdi.

Accurate Diagnostic Reporting is IMPORTANT

As you know, it is a requirement to report hearing screens and evaluations for children under 3 years of age. Some providers have chosen to enter the results directly into the database, eSP. Others report by sending in an outpatient screening form or a diagnostic paper reporting form. For those using a paper reporting form, it is important to remember that your work will be entered into eSP by another person, oftentimes by someone who is not an audiologist. It becomes difficult to interpret test results when forms are not complete. To make sure the child you tested receives the most appropriate follow up if seen by another provider, and to maintain an accurate state database, it is essential that these forms reflect your test and recommendations accurately. Please make sure you are completely filling out the forms, including results obtained, method of testing, impressions (severity and type of hearing loss) and recommendations. If recommendations are not included on the reporting form, EHDI staff has a more difficult time following up with the family, as they do not know the guidelines for follow up that you have given the family.

Recall that transient conductive hearing loss lasting for less than 90 days does not need to be reported (see www.idph.state.ia.us/iaehdi/common/pdf/iaehdi_admin_rules.pdf to review EHDI law and administrative rules). It is not necessary to submit a paper reporting form if you have only completed tympanograms. By submitting information regarding a transient conductive hearing loss, the child's eSP file will indicate he or she is in need of follow up. If you choose to submit the form, then it is essential to submit the follow-up test results to EHDI. If not, the child's file remains 'open' and EHDI staff must use time and resources to track down the follow-up test, which may or may not have taken place.

If you have questions regarding diagnostic reporting, please contact Tammy O'Hollearn. Her contact information is on the back of the newsletter. Thank you all for doing what you can to assure Iowa's children receive timely and appropriate audiologic follow up!

A Sound Beginning for Your Newborn Baby

To order additional hearing screening brochures in English or Spanish, please call the Healthy Families Line at 1-800-369-2229. Ask for publication IDPH 131 (English) or IDPH 131(S) (Spanish). The brochure is available free of charge!

Healthy Families Line: 1-800-369-2229
Phones are answered 24 hours a day, seven days a week

What NOT to tell Parents...

- Fluid in the ear caused your baby to fail the hearing screen. It may be the reason, but we don't know that for sure and it minimizes the importance of returning for the follow up.
- This happens all the time, don't worry. This minimizes the importance of returning for the follow up.
- Your baby was too fussy and I couldn't get a good test. This suggests that you are not very good at doing what you need to do to get a baby tested.
- Your baby has a hearing loss. This is only a screening, meaning that we need to test the baby again. The only thing we know for sure is that baby didn't pass at this time.

See the Communication Guide for Communicating Hearing Screening Results on the EHDI Web site at:

www.idph.state.ia.us/iaehdi/common/pdf/parent_communication_guide.pdf.

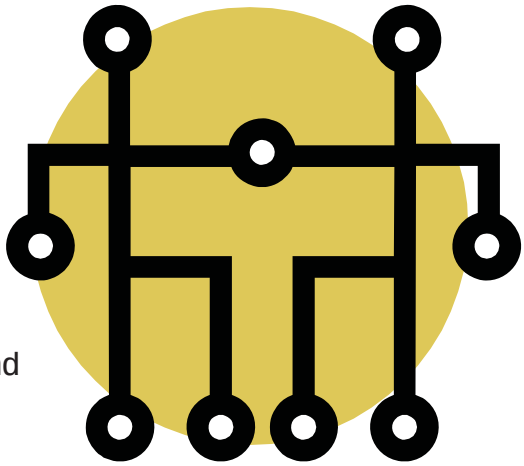
Welcome Meghan!

The Iowa EHDI program would like to welcome Meghan Wolfe! Meghan is located in the Iowa Department of Public Health office and will split her time between EHDI and Early ACCESS (EA) programs. For the EHDI program, Meghan will implement day-to-day follow-up activities to ensure children receive follow-up hearing screens and or assessments including, but not limited to: contact hospitals or outpatient screening facilities to confirm hearing screen results, preparing and sending EA EHDI referrals to EA, preparing and sending follow-up/high risk factor letters to families and/or physicians and keeping and preparing statistics on referrals sent and referral outcomes.

Meghan's role with the EA program is to provide consultation, technical assistance, and training pertaining to EA service coordination for lead poisoned children with Title V contract agencies. Meghan facilitates the development of training curricula and tools to assist Title V contract agencies in EA service coordination documentation and family meetings for lead poisoned children. In addition, she is also responsible for monitoring quality of documentation provided by EA service coordinators on the Individualized Family Service Plans for those same children.

Meghan earned her undergraduate degree in social work from the University of Iowa. After college Meghan worked as a medical social worker for a home health organization and was a contracted employee for Johnson County Public Health. Meghan relocated to Des Moines and began working at IDPH two years ago. She began her work at IDPH as an intern and transitioned to an emergency employee working with the Early ACCESS liaison for IDPH until she was hired into this position in February 2009.

Successful Partnership Results in Timely Services for Children



In 1997, Tanya Harper Rowe, an audiologist at Hearing Associates, P.C., along with pediatric physicians Norma McGuire, M.D. and Patrick Beck, M.D., with the cooperation of Sandy Holden, nursing supervisor of the Mercy Medical Center North Iowa Newborn Nursery worked together to begin the Newborn Hearing Screening Program at Mercy Medical Center North Iowa. Since that time, a three-way cooperative partnership has ensued between Mercy Medical Center North Iowa, AEA 267 and Hearing Associates, P.C. for newborn hearing screening, follow-up and monitoring for high risk or hearing impaired infants and children.

Since its inception, the process has evolved so that each partner involved plays a specific role in screening, identification, tracking and habilitation of newborns with and without hearing loss. Newborns are screened at the Mercy Medical Center North Iowa Newborn Nursery. Those who pass Transient Evoked Otoacoustic Emissions (TOAE) without high risk factors have completed the hearing pathway. Children who pass the newborn screening but are born with a high risk factor are monitored with Delayed Progressive Incidence (DPI) screenings as recommended by the Joint Committee on Infant Hearing Screening at either the AEA 267 Clear Lake office or Hearing Associates, P.C.

Children who fail the newborn screening are referred to AEA 267 Clear Lake office for a repeat screening and impedance measures if needed, preferably by 2-weeks of age. AEA 267 has a designated time reserved each week for testing babies that have failed the newborn hearing screening, babies that were missed, and babies that are scheduled at 6 months of age due to a high-risk factor. The nurses at the hospital schedule the appointment for the baby during one of those times. The nurses then fax the information to AEA 267 regarding the baby, the reason for referral and the appointment time. Once the fax is received by AEA 267, the baby is scheduled into the hearing clinic, and a reminder card is sent to the family to remind them of the appointment. Parents are contacted to change their appointment to an AEA 267 office that is closer to home, when appropriate. Fortunately, audiologists at the AEA 267 office have the capability of portable TOAE, and they have been able to reach infants without transportation capability for retesting. If the child fails the two week screening, depending upon the OAE and high-frequency tympanometry results, the baby is either referred to their physician or referred to Hearing Associates for a diagnostic ABR.

Hearing Associates initial test battery consists of Distortion Product Otoacoustic Emissions (DPOAE) testing, impedance measures, including multi-frequency tympanometric and acoustic

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In a Family's Own Words…

You might remember this child from the last newsletter where this family talked about the Guide By Your Side program! Unfortunately, we were not able to put the two articles together in the same newsletter, but we thought it was important to hear about their experience with newborn hearing screening and follow up. There are lesson we can learn from their experience.

Our son, Lucas, was born on his due date, August 31, 2007, at a hospital in Iowa. While I was in labor, I developed a fever and Lucas got an infection and therefore had to spend the first week of his life in the Neonatal Intensive Care Unit. While we were in the NICU, Lucas had his hearing screened. The screen was by chance though. The employee was screening a baby next to us and happened to ask us if our son had already been tested because he was not on the list of infants to be screened. We told her he had not been screened. She took down our information and proceeded to screen him. Lucas did not pass the first test. At that time, it was explained to us that more than likely there was nothing wrong and that a lot of children do not pass the initial screening. During that week, they tested Lucas at least two more times and both times he failed. They gave us a pamphlet and asked us to follow up. We made an appointment with the audiology department at the hospital where he failed another hearing screen. During the outpatient hearing screen, the audiologist appeared to become frustrated because my son got a little fussy and squirmy and needed to eat. Kids are not programmable. They cannot be turned on and off, but I was a new mom and didn't say anything. Lucas was then referred to the Area Education Agency (AEA) in our area for another screen.

At the AEA office, Lucas was screened again and actually passed in his right ear and failed in his left ear. The AEA audiologist referred us to Iowa City to have an ABR done, but didn't really make a big deal of it. Now it is December of 2007 and we were in Iowa City with Lucas having the ABR done. In the middle of the test, Lucas woke up and one of the audiologists came in to tell us that although they were not able to finish the test, they could definitively tell us that Lucas would need hearing aids in both ears.

We were shocked and completely unprepared for the results! Not to mention the fact that he had just passed a hearing test in his right ear. Although we understood that he was not passing his hearing screens, we did not truly understand the full implication of what not passing meant. Again, we were overcome with every emotion possible, including grief. I don't remember at all at the time thinking that hearing loss could be a possibility. I thought we were going to Iowa City to figure out what needed to be fixed; not that it may be something that couldn't be fixed.

Throughout the initial hearing screening process, until we were seen at the AEA, everyone kept assuring us that there was probably nothing wrong and so that is the attitude we adopted. No one explained to us what the failed screens could mean. Given the fact that Lucas spent his first week in the NICU on Gentamycin, I think someone somewhere should have realized the risk and at least mentioned the risk to us. We did not learn

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Successful Partnership Results in Timely Services for Children

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reflex probes. These tests are administered by all audiologists in their office. Additional test protocol consists of screening or diagnostic Auditory Brainstem Response (ABR) evaluations, as well as steady-state response (ASSR) test for infants older than 3 months of age or for babies who continue to show hearing impairment. Diagnostic brainstem measures are administered by audiologists Stuart Trembath and Linda True. Their protocol allows for the differential diagnosis of conductive, sensory, and/or neural hearing impairments.

Following diagnostic evaluation, Hearing Associates has the privilege of working closely with the families of children with hearing impairments to fit their children with hearing aids and other assistive devices. Habilitation of infants with hearing loss may consist of hearing aid fittings at Hearing Associates and speech, language and aural rehabilitation services through Early Access for Children and Families and AEA 267. Additionally, referrals to local ENT physicians, pediatricians, cochlear implant programs, family organizations such as "Guide by Your Side," and genetics counseling specialists allows the children and families to obtain the assistance they need to be successful.

If you are interested in speaking with one or more of these partners, please contact Tammy O'Hollearn, tohollea@idph.state.ia.us for their contact information.

North Iowa Community Action Staff:

Front row: Nurses Deb Rickard and Beth Curry.
Back row: Nurses Linda Als, Beth Buckholtz and Diane Hansen.
Not pictured: Brittnee Meyer, Kristie Lovik, Sally Leider, Sue Nystrom, Stephanie King, Cindy Hoffman, Sara Berkley, Jane Roggensack, Rene Keiser, Kristin McHenry, Rochelle Arends, Emily Hurd, Patti Reimers, Diane Lee, Teri Echoff, Aimee Eastman and Amanda Fjeld

AEA 267 Staff:

Seated (L to R): Audiologists Collette Sampson, Marlys Ebaugh and Julie Zahner
Standing (L to R): Audiometrists Sharon Mihm and Sue Eichmeier

Hearing Associates Staff:

Seated (L to R): Audiologists Gary Dockum and Stuart Trembath.
Standing (top L to R): Audiologists Linda True, Tanya Harper Rowe, Rachel Dolezal.

In a Family's Own Words…

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of the link between Gentamycin and hearing loss until a friend of the family gave us that information, which was almost four months after the initial failed screening.

During our appointment in Iowa City, the audiologist gave us a booklet of information regarding hearing loss. I was extremely thankful she gave us that information because it was close to the holidays and everyone was busy, so it wasn't until after the holidays that we were able to fully discuss Lucas' situation with anyone.

For the EHDI program, a couple of things/ problems stand out about our story at this point:

- Lucas almost missed his screening because he was not in the system, and we would have never caught his loss until he began talking because he can detect many sounds.
- No one connected, or at least told us about, the failed hearing tests and the fact that he was on Gentamycin and in the NICU for a week which are both risk factors for hearing loss.
- No one gave us any information telling us what his failed screens could mean. It appears as though no one wanted to scare us, so instead they just kept saying, "it is probably nothing." This left us unprepared and in complete shock when we learned of his loss.
- In order to increase follow up I think you need to DRILL it into parents whatever way you can that even though it may be nothing, it is important to follow up if your child fails their hearing screen. Because, IF there is something wrong, the earlier you catch it and work to alleviate it, the better your child will do developmentally. After all, everyone wants to give their child the best start.

"I also want to say that the AEA audiologist who works with our son continually astounds me now. She goes to great lengths to help us! In addition, I was able to connect to a Guide by Your Side representative last fall who was wonderful. I was able to ask her a lot of questions and get her contact information in case I had more questions later. Thank you for letting us share our story."

Following the diagnosis, we were reconnected with the AEA. Looking back, I think the minute someone finds out their child has a hearing loss and AEA steps in to help, so should someone who has been there before. The first meetings were a blur and having someone sit down with us to discuss the real-life aspects of this "diagnosis" would have been helpful. The professionals are great, but the majority of them have not been in our situation.

That being said, I also want to say that the AEA audiologist who works with our son continually astounds me now. She goes to great lengths to help us! In addition, I was able to connect to a Guide by Your Side representative last fall who was wonderful. I was able to ask her a lot of questions and get her contact information in case I had more questions later. Thank you for letting us share our story.

Read about lessons learned from Lucas' story on page 8.

EHDI Law and Rules Amended

Iowa Code was amended in the 2009 legislative session. The first amendment requires hospitals to report newborn hearing screening results and risk factors associated with hearing loss to the child's primary care provider (PCP). This change will help facilitate more timely follow-up as the PCP can address the need for a follow-up hearing screen at the infant's 2-week check up. The second code change requires hospitals to document the PCP who will assume the newborn's care upon discharge. The revised language in the Iowa Code overcomes a previous barrier related to hospitals identifying the newborn's PCP at the time of birth rather than at hospital discharge, which hindered the follow-up process. Additional language requires audiologists or other health care providers who provide hearing screens, re-screens or diagnostic assessments to report findings to IDPH-EHDI within six days. This requirement is consistent with the requirement that hospitals reporting the initial newborn hearing screen must do so within six days. These changes have proven to help other states decrease the number of children "lost to follow-up" and/or assist with more timely intervention, if needed. These changes will also alleviate unnecessary follow-up and referrals for both families and primary care providers.

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Lessons Learned from Lucas' Story...

There are a few things that stand out in this family's story that we can all learn from. We feel it is important to keep sharing family stories so we can celebrate our successes and learn from those stories that may have had "bumps" along the way. We have outlined some lessons below:

1. Don't ever down play a child not passing their hearing screen. If a child does not pass their screen, you could say to a family, "Your baby did not pass their hearing screen today. This does not necessarily mean that your baby has a permanent hearing loss, but without additional testing we can't be sure. (Explain your protocol for re-screening and set the appointment at that time.) The hearing screen results will be provided to your baby's doctor. Please be sure to make or keep the appointment for further testing."
2. If a child fails a second hearing screen at the hospital, they should automatically be referred to a pediatric audiologist for diagnostic assessment. Avoid multiple outpatient screens.
3. Talk to the family about risk factors for hearing loss and the importance of follow up.
4. Provide some tips in advance of the appointment that may help facilitate a more productive appointment. Show empathy and patience. It goes a long way, especially with new parents!

Newborn Hearing Screening Established in Some Amish Communities

EHDI staff recently noticed a trend associated with Iowa's Amish population either refusing newborn hearing screenings or leaving the hospital too soon to be screened. As a result, the children were eventually labeled as a "lost contact" after unsuccessful attempts were made to reach the family to bring them in for a hearing screen. The state genetics coordinator met with two Amish Elders to explore their feelings about newborn screening (metabolic and hearing) through the HRSA Family Participation Project. The elders said they were not opposed to either screening.

In February 2009, the EHDI coordinator and follow-up coordinator met with the regional AEA audiologists and representatives from two Amish communities to identify barriers related to newborn hearing screening and develop a plan to address these barriers. The result was that an article was published in the Grapevine, which is a newsletter that goes to all Amish families in Iowa, stating that hearing screening would be provided free of charge at a location in Drakesville and Kalona. The article encouraged families of newborns and infants to bring their children in for a hearing screen. An elder in Drakesville offered his home and in Kalona hearing screenings take place at the Community Clothing Closet. The EHDI personnel have also encouraged elders in any other Amish communities in Iowa to contact the EHDI program to facilitate screening in their communities.

We want to especially thank Peg Maher with Grant Wood AEA and John Nelson with Great Prairie AEA for setting aside time every other month to screen babies in those communities.

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EHDI Law and Rules Amended

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Administrative rules that support changes in Iowa Code are drafted and will be noticed in June with a period of time for public comment. A public hearing will be held the first week in August. The administrative rules have the same changes as the code listed above. In addition, a new section has been added which establishes procedures for the distribution of funds to support the purchase of hearing aids and audiological services for children in accordance with the appropriation designated to IDPH for this purpose (83GA, HF811). The revised Iowa Code and administrative rules were presented to the EHDI Advisory Committee members last fall and again in May 2009. A copy was also provided to the Audiology Board staff in the fall.

Newborn Hearing Screening Established in Some Amish Communities

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Both Peg and John are also working with the midwives in those communities to get the word out and assist them in reaching families of newborns.

We also want to thank Kim Lestina with Grant Wood AEA for her expertise in working with the Amish community. This effort has already led to the development of similar initiatives for older children. Thank you to those hospital personnel who made case notes in eSP when an Amish family left within a few hours of giving birth and prior to a newborn hearing screen! We believe that this will make an impact, even if it is small, on our lost to follow up and children getting the services they need to be successful.

Tips for Reporting Risk Factors Accurately

The EHDI program sends letters to the families and primary care providers (PCPs) of children who have one or more risk factors marked in eSP. The letters provide information about why these children need additional testing and when and how it should be done.

The information we provide to families and PCPs is only as good as the risk factor information reported in eSP. The following tips will help you enter accurate risk factor information in eSP:

- **Family history of childhood hearing loss:** Report only if there is a history of childhood hearing loss.
- **Congenital infection:** Report only if the infection is confirmed in the baby. If the mother has an infection, list it in a case note.
- **NICU:** Report only if the baby was in the NICU for more than five days.
- **Head injury:** Include a case note explaining the circumstances. We want to be sensitive in cases of child abuse.
- **Quality assurance:** Double check your work to ensure the risk factors marked are truly the risk factors that child has.
- **PCP:** Verify the PCP with the family so the risk factor (and any other follow-up correspondence) will be sent to the PCP that follows the baby after discharge.

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Tips for Reporting Risk Factors Accurately

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Hospital staff members can take the following steps to educate parents and PCPs about risk factors for late onset hearing loss:

- Talk to families about their children's risk factors. Explain that they need further testing even if they pass the newborn hearing screening.
- Provide parents with the Iowa EHDI brochure and point out the speech and language milestones on the back cover. This will help parents determine whether additional testing is needed before the recommended age.
- Provide families with the EHDI Web site address, which includes a link to the Joint Committee on Infant Hearing Screening's recommendations regarding risk factors and the literature to support their recommendations; www.idph.state.ia.us/iaehdi/default.asp.
- Record risk factors in eSP accurately.
- Notify PCPs of their patients' risk factors.

We welcome your questions, comments and suggestions about this newsletter. Please forward any feedback about Iowa EHDI News to:

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Infant Hearing Screening Equipment Loaner Program

Are you having problems with your hearing screening equipment? The Iowa EHDI program has a limited number of loaner screening OAE units available for hospitals to use while their screening equipment is being repaired.

There is no charge for borrowing the equipment.

For information about loaner units, please contact:

Marilyn Dolezal - (319) 353-6233

Lenore Holte - (319) 356-1168

Emily Andrews - (319) 384-6894

Nick Salmon - (515) 576-5312

Your single point of contact to assist families in connecting with Early ACCESS and community-based services that address specialized child and family needs

1-888-IAKIDS1 or
1-888-425-4371

www.EarlyACCESSIowa.org

Contact Information

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Additional copies of Iowa EHDI News are available by contacting Tammy O'Hollearn.