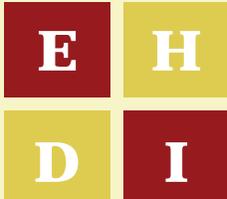




EHDI Site Visits...Coming to a Hospital Near You

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Over the next year to year and a half, the EHDI program personnel plan to visit all birthing hospitals in Iowa. The EHDI team will consist of a state EHDI staff member, audiology technical assistant, and parent of a child who is deaf or hard-of-hearing. The goals are simple:

- Gain a better understanding of how well-baby and NICU EHDI programs are structured and operate
- Identify strengths and needs of each birthing facility's EHDI program
- Share best practices with each facility
- Develop a clearer picture of hospital and technical assistance needs

We believe hospital staff will also benefit. Hospitals will learn ways to build on the strengths of their programs and improve identified need areas based on best practices within the EHDI community.

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Advisory Update

The next meeting of the Iowa Early Hearing Detection and Intervention Committee is:
October 2, 2008
 10 a.m. - 3 p.m., Iowa Dept. of Public Health, Lucas State Office Bldg., Rm 518

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.

EHDI Site Visits...

Coming to a hospital near you

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In addition, hospitals will learn about resources that may assist them in implementation and hear from a parent whose life has been impacted by the work they do.

Ultimately, we believe that the quality and consistency of Iowa EHDI programs and services will improve for families with fewer babies being missed or lost to follow-up, and the quality of data collection will improve.

Iowa Pediatric Hearing Health Care Resource Directory

Iowa is in the beginning stages of development of a pediatric audiology resource directory similar to a directory developed in New Jersey. The purpose of the directory is to assist parents and professionals in locating a variety of pediatric audiology and hearing aid dispensing providers throughout the state of Iowa and neighboring communities.

The directory will be available online and in limited hard copies. A letter of invitation and directory survey were mailed to all audiologists, ENT doctors, and hearing aid dispensers in June. If you have not yet completed the survey, please do so by August 15th so the directory can be as comprehensive as possible. Fax the completed form to Tammy O'Hollearn at (515) 242-6013.

Risk Factor Letters Go Out

Children with certain risk factors are at greater risk of developing late onset or progressive hearing loss. These children may pass the newborn hearing screening but develop a hearing loss later. The Joint Committee on Infant Hearing recommends these children have an audiological assessment by six months or 24 to 30 months, depending on the risk factors they have.

The Iowa Early Hearing Detection and Intervention (EHDI) program is now sending letters to families and primary healthcare providers (PCPs) of children with risk factors. The letters provide information about recommended follow-up and resources for more information. We need your help to make this process efficient and accurate. You can help by:

- 1 Telling families** their child has a risk factor and explaining that a hearing assessment will be needed at a later date.
- 2 Marking risk factors in eSP records.** We cannot notify families and PCPs if we do not know about the risk factors.
- 3 Making sure the risk factors you are making are correct and confirmed.** For example, before marking "congenital infection," be sure the baby is affected.
- 4 Listing the PCP that will see the child after discharge from the hospital (i.e. for well-child checks, etc.).** We send the letter to the PCP listed in eSP, and have had several calls and faxes stating that the PCP is incorrect.

If you have questions about this process, please contact Erin Kongshaug (contact information is on the back cover). Thank you for your help!

Hearing Aids and Audiological Services

Funding Renewed

Good news for Iowa families who have children with hearing loss... the Iowa Legislature appropriated \$238,500 for a second year to the Iowa Department of Public Health (IDPH) to purchase hearing aids and audiological services for uninsured or underinsured Iowa children under the age of 21.

The new funding is available July 1, 2008 through June 30, 2009 or until funds run out. Claims will be processed on a first come, first serve basis and are considered as payor of last resort. Reimbursement is based on Medicaid rates. If you know of a child(ren) in need of hearing aids or audiological services, please visit the EHDI Web site at www.idph.state.ia.us/iaehdi/default.asp.

Click on "Parents" or "Professionals" to find the funding announcement, application and frequently asked questions sheet or contact Tammy O'Hollearn at tohollea@idph.state.ia.us or 1-800-383-3826.

In five months (January 2008 - June 2008), IDPH received 128 applications for this funding to assist with the costs of hearing aids, ear molds, FM systems, batteries, and diagnostic testing. Of the 128 applications, 117 applicants had medical insurance. Screening and diagnostic testing are typically covered; however hearing aids are not. We expect that most of the money will be expended when final claims are processed.

EHDI Program Receives CDC Funding

Iowa's EHDI program is a collaborative effort of two projects, one funded by the CDC and one funded by the Health Resources and Services Administration (HRSA). The two projects work together seamlessly to achieve a comprehensive and coordinated statewide EHDI system. They are co-located at the IDPH Bureau of Family Health, Iowa's Title V program for maternal and child health.

The EHDI program just learned at the end of June that IDPH will be awarded a grant in the amount of \$180,042 each of the next three years. Watch for opportunities to work with the EHDI project staff to improve the Iowa EHDI system!

Valuable Addition to EHDI Web Site for Professionals

The EHDI program has added a new section to its Web site under the professionals tab entitled, Clinical Information and Educational Materials. New information includes:

- Amplification, Implants and FM Systems
- Congenital Cytomegalovirus (CMV) Infection & Hearing Loss
- Genetics of Early Childhood Hearing Loss
- Joint Committee on Infant Hearing Statement 2007
- Late Onset Hearing Loss in Infants and Young Children
- Medical Care for Sensorineural Hearing Loss
- Mild and Unilateral Hearing Loss in Children
- Pediatric Auditory Neuropathy/Dys-synchrony

Hospitals Caught Using Best Practices

Broadlawns Sets Out to Decrease Children "Lost to Follow-Up"

Currently all babies born at Broadlawns have an initial hearing screen in the nursery. Out of those tested, 18% or about 90 per year fail the initial screen. The nursery at Broadlawns has a vent that runs, which often makes it difficult to get good hearing screen results. If the patient rooms are full, there is no other place to take the babies to screen in quiet. As recommended by the Joint Committee on Infant Hearing, all babies should be screened by one month of age, diagnosed by three months of age and receive early intervention services, if needed, by six months of age. Until now Broadlawns referred children in need of a re-screen to the Heartland Area Education Agency. Many of those children who were referred never received a second screen and were "lost to follow-up", even after multiple attempts to get the children back in.

During a recent site visit, the Broadlawns nursery staff, state EHDI program, and Heartland AEA staff discussed the issues surrounding re-screens. Sandi Steele, RN, who oversees the EHDI program in the Broadlawns nursery, said that transportation is a large barrier for their families. Although Heartland AEA has sites in various locations in central Iowa, the closest sites for families in the Des Moines area are Ankeny and Indianola. In addition, many families served by Broadlawns prefer to return there for care because they can receive most follow-up care at one time at a place familiar to them. The team then discussed the possibility of re-screening children at their two week check-up at Broadlawns. Sandi took the idea to the administration to explore doing re-screens specifically in their pediatric clinic as a way to ensure children they had served in the nursery received needed follow-up hearing screens.



Pictured:

Larissa Jeter, Ellen Stance, Rosa Stougaard, Dr. Scott Barron, Linda Chase

Broadlawns applied for a Community Betterment Grant through the Polk County Board of Supervisors to pay for the cost of an AuDX System. They were successful! Broadlawns will soon have the ability to re-screen children who did not pass their newborn hearing screen during their well child visit. They also plan to use the screening device as a tool for children with middle ear problems, so they can make appropriate follow-up referrals. Hats off to Broadlawns in their effort to decrease the number of children born at their hospital being "lost to follow-up!"

MARK YOUR CALENDAR!

Iowa Symposium on Hearing Loss:
Impact on Children and Their Families

September 19 & 20, 2008
ISU Center Scheman Building
Ames, Iowa

Topics to include:

- * The Deaf child's bill of rights
- * Auditory-Verbal therapy
- * The genetics of childhood hearing loss
- * Reducing loss to follow-up in EHDI programs
- * Real-ear verification of amplification for infants and toddlers
- * Monitoring children at risk for delayed onset hearing loss
- * Parent and teen panels



For more information

Contact Sara Patkin at
m spatkin@yahoo.com or
(515)963-8664.

Watch for registration
materials in Spring 2008.
CEUs available.

Boone County Hospital Rescreens...

A Success Story

Retests on newborn screening referrals can often be difficult to achieve consistently. At Boone County Hospital (BCH) in Boone, Iowa they set up a process that has enabled them to achieve a 100% follow-up rate on referral rescreens.

Each baby is screened up to three times on each ear prior to discharge as recommended in the newborn hearing screening protocol. If the baby "refers" in either ear, nursing staff at BCH schedules an appointment for a rescreen in their nursery at two weeks of age. The parents are notified of the pass or refer status verbally and in writing in the form of a preprinted letter. The appointment scheduled prior to the infant's discharge from the hospital is included on the bottom of the letter. The rescreen is entered into the daily scheduling book along with the parent's name and phone number.



Pictured:

Gina Wolter, RN; Dena Sytsma RN, BSN; Autumn Grossnickle, RN

Nursing staff report, "parents have been very receptive and responsible with follow-up."

Mary Greeley Medical Center - Unique & Effective Rescreen Follow-Up

Lucinda Hollingshead, an RN at Mary Greeley Medical Center in Ames takes rescreens seriously! She is the primary person to enter newborn hearing screen results into eSP. If she sees that a baby from their nursery referred (did not pass) the newborn hearing screen, she enters that information into a tickler file. Approximately 2-3 weeks after the discharge, she contacts the parents by phone to ensure they have followed up and obtained a rescreen for their baby or to remind them of the need for their baby to having a hearing rescreen.

Lucinda offers assistance if they do not remember where they can go to obtain hearing rescreen. Lucinda says, "I have found parents to be positive and appreciative of the call."

A Life Remembered...

It is with sadness we report the death of Joyce Andre. She was the founder of the Deaf Awareness Walkathon and member of the EHDI Advisory Committee



(representing Iowa Association of the Deaf). Joyce spent countless hours teaching sign language and was a volunteer in every aspect of the deaf community.

Joyce's positive attitude, infectious smile and tireless work will be missed by all whose lives she touched.

Special Considerations for Screening

The 2007 Joint Commission for Infant Hearing (JCIH) statement recommends separate protocols for infants in the well-baby nursery and babies that spend more than 5 days in the NICU. Babies in the NICU are at higher risk for neural hearing loss, known as auditory neuropathy or auditory dyssynchrony. Much remains unknown about auditory neuropathy/auditory dyssynchrony (AN/AD), but children requiring a NICU stay of 5 or more days appear to be at higher risk for the condition.

Auditory neuropathy/auditory dyssynchrony is characterized by normal Otoacoustic Emissions (OAE) responses and abnormal or absent Auditory Brainstem Response (ABR). Therefore, it is important to consider the implications of your protocols and procedures for birth admission hearing screens and for hearing re-screens. JCIH recommends automated ABR as the only appropriate hearing screening method in the NICU. If an infant does not pass this hearing screen, they should be referred to an audiologist for re-screening and possibly for diagnostic auditory brainstem response testing. These infants SHOULD NOT be re-screened with Otoacoustic Emissions. If you use ABR screening for infants in a well baby nursery and they do not pass the screen, they should also be rescreened using automated ABR, not OAEs. The JCIH statement may be found online at www.jcih.org.

More information about auditory neuropathy/auditory dyssynchrony may be found at www.nidcd.nih.gov/health/hearing/neuropathy.asp.

Pediatrician's Toolkit for Auditory Neuropathy



- Recognize tests used for newborn hearing screening OAE vs. AABR. OAE only screening programs will miss every child with AN/AD.
- Refer infants with risk factors, if OAE is only screening available. For list of risk factors go to: www.idph.state.ia.us/iaehdi/common/pdf/risk_factors.pdf.
- Children with unexplained speech and language concerns should have a hearing evaluation, even with a normal hearing screen.
- Treatment approach is based on individual auditory skills and needs.
- Trial with hearing aids should be initiated once behavioral audiometric results are obtained.
- Cochlear implantation can be an effective solution.
 - MRI should be performed to rule out VIIIth nerve deficiency

Importance of Reporting Hearing Screen Results to PCP

The Joint Committee on Infant Hearing (JCIH) stresses the following communication directly from a representative of the hospital hearing screening program to the Primary Care Provider (PCP) each infant in their care: 1) results of the screening test (pass, did not pass/refer, miss) and 2) recommendations for follow-up for children who did not pass/referred or were missed.

Children's primary care professionals (i.e., the medical home or PCP) are essential members of the EHDI system. An infant's pediatrician or other primary health care provider is responsible for monitoring the general health, development, and well-being of the infant. They are also in a great position to advocate for the child and family; thus the importance of hospitals notifying physicians of the newborn hearing screen results. Often the primary care professional is the first one to see a child after they leave the hospital following discharge. It is essential for the PCP to have the newborn hearing screen results during that initial visit so they can further coordinate follow-up care for the children who do not pass their newborn hearing screen, were missed, or have high risk factors.

Just as primary care professionals assume responsibility for a child that does not pass their newborn metabolic screen, they must accept responsibility for children who do not pass their newborn hearing screen to ensure a rescreen or audiological assessment is conducted. If applicable, they must also initiate referrals for medical specialty evaluations necessary to determine the etiology of the hearing loss. The medical home algorithm for management of infants with either suspected or proven permanent hearing loss is provided on the EHDI Web site at www.idph.state.ia.us/iaehdi/common/pdf/nhs_diagnosis_checklist.pdf.

Help the EHDI program and PCPs ensure children receive timely follow-up services by reporting newborn hearing screen results to the PCP as recommended by the Iowa EHDI program and JCIH. The work you do now could impact a child's life for many years to come!

American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The medical home. *Pediatrics*. 2002;110 :184 –186

Joint Committee on Infant Hearing. (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *American Academy of Pediatrics*. 120: 898-921

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

Early ACCESS Iowa

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



**Requests?
Feedback?
Comments?
Suggestions?**

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

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

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