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Unilateral Hearing Loss

Some parents and professionals question the importance of providing follow-up services to children with hearing loss in one ear and normal hearing in the other. The new 2007 position statement of the Joint Committee on Infant Hearing makes a clear recommendation to follow babies who have unilateral hearing loss, for several reasons. These reasons can be important for medical management or for later academic achievement.

Permanent unilateral hearing loss can be caused by several factors, some of which are important to know for medical reasons, such as enlarged vestibular aqueduct (EVA) or congenital cytomegalovirus (CMV). Especially in the case of congenital CMV, the child is at high risk to develop hearing loss in the other ear. While it is true that young children with unilateral hearing loss often reach early speech and language milestones on time, they have difficulty localizing the source of sound, which can be a safety concern, and difficulty understanding speech in noise environments. The ear with the hearing loss can frequently be fit with a hearing aid, which will help localization and communication development. Research also shows that children with unilateral hearing loss perform more poorly in school on reading achievement and other areas that require verbal skill. If the ear with hearing loss is not eligible for a personal hearing aid, other classroom amplification systems, communication and teaching strategies will help.

Advisory Update

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

April 2, 2009

10 a.m. - 3 p.m., Location: TBD

April						
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We would like to welcome the following new members to the committee:

Dr. Jeffrey Hoffman
Lucinda Hollingshead, RN
Bob Vizzini, ASL Instructor

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

Iowa EHDI Program... Moving Forward!



The Iowa Early Hearing Detection and Intervention (EHDI) system has come a long way in the last few years. Progress has been made in the following areas: screening and reporting, referral and follow-up, quality assurance, education, and funding. With progress comes new challenges, but there are also opportunities to build a more sustainable, comprehensive coordinated EHDI system. The following article is a summary of a presentation given by Tammy O'Hollearn, Iowa EHDI Coordinator and Erin Kongshaug, EHDI Follow-Up Coordinator at the 2008 Iowa Symposium on Hearing Loss.

Progress

Screening and Reporting - Almost all Iowa hospitals had a newborn hearing screening program prior to passage of the Iowa newborn hearing screening law. Since the law went into effect on January 1, 2004, all Iowa birthing hospitals have been screening babies' hearing before discharge. Hospitals and other screening facilities now report all results for children under age three to the Iowa Department of Public Health (IDPH). This allows the EHDI program to track individual children throughout the follow-up process.

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Great Resource for Parents and Professionals... www.babyhearing.org

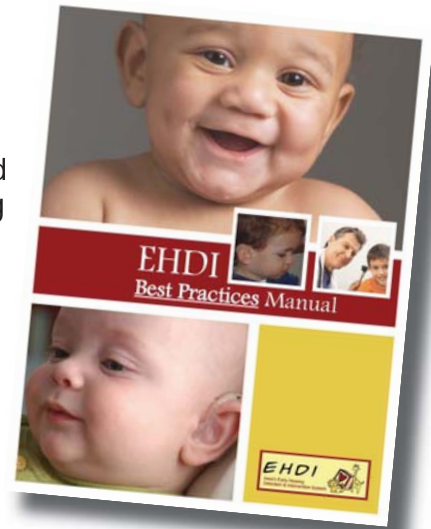
Many professionals are involved in supporting infants and families following newborn hearing screening (NHS). Teams include healthcare providers, audiologists, service coordinators, early interventionists and other specialists. Each of these professional disciplines contributes unique expertise, while serving the family in collaboration with other team members. The resources found at <http://www.babyhearing.org/Audiologists/index.asp> are designed to support professionals in carrying out their roles.

Several educational modules are offered and some are discipline specific. Downloadable resources to use for community and/or parent education may also be accessed from this page. Parent Education Resources and Fact Sheets sub-sections contain downloadable PDFs that all visitors are welcome to use in their work with families. There are also sections for parents describing the newborn hearing screening process, information about hearing loss, options and so forth.



Coming Soon - Site Visit Rubric and EHDI Best Practices

The Early Hearing Detection and Intervention (EHDI) program is pleased to announce that the EHDI Best Practices Manual is complete and being sent to print as this newsletter is being written. The purpose of the EHDI Best Practices Manual is to advance the development of a comprehensive statewide EHDI system in Iowa. The manual was developed to assist hospitals, birth centers, Area Education Agencies, health care providers and private practice audiologists in developing programs and written protocols for newborn hearing screening, follow up and intervention. The manual is based upon best practices within early hearing detection and intervention programs and Iowa EHDI law and rules.



The EHDI program would like to thank the following individuals for their time and expertise in the development and review of the manual:

Emily Andrews, Pediatric Audiologist, Center for Disabilities and Development, University of Iowa Children's Hospital; Margaret Christiansen, Audiologist, Audiology Consultants; Valorie Caputo, Educational Audiologist, Green Valley Area Education Agency; Marsha Gunderson, Audiology Consultant, Iowa Department of Education; Diana Hanson, Pediatric Audiologist, Iowa Methodist Medical Center; Lenore Holte, Professor of Audiology, Centers for Disabilities and Development, University of Iowa Children's Hospital; Angie Jenkins, Audiologist, Physicians Clinic of Iowa ENT; Erin Kongshaug, EHDI Follow-Up Coordinator, Child Health Specialty Clinics; Joan Marttila, Audiologist, Mississippi Bend Area Education Agency; Deb Moon Davis, Educational Audiologist, Heartland Area Education Agency; Tammy O'Hollearn, State EHDI Coordinator, Iowa Department of Public Health; and Nick Salmon, Audiologist Technical Assistant, Center for Disabilities and Development, University of Iowa Children's Hospital.

In addition to the best practices manual, a site visit rubric is being finalized for hospital visits. The rubric can be used by hospitals to conduct a self assessment prior to the EHDI site visits and will be used by EHDI program staff to gain a better understanding of hospital strengths and needs. In addition, the EHDI program will develop a clearer picture of hospital technical assistance needs. Look for the manual and rubric in February! AEs and audiologists serving large numbers of children will also receive a copy of the manual at the same time. A rubric for site visits at these locations will be developed and disseminated at a later date.

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

Iowa EHDI Program... Moving Forward!

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Referral and Follow-up - In May of 2007, the EHDI program began referring babies who missed or did not pass their hearing screenings to Early ACCESS. Early ACCESS staff members then contact families, encourage them to get the hearing follow-up services their children need, and tell them their options for scheduling an appointment.

IDPH has changed the rules to allow communication with our border states. IDPH can now refer out-of-state residents born in Iowa to the EHDI programs in their home states. Our border states and some border hospitals have also begun providing hearing screening results to the IDPH for babies born in Iowa who transfer to hospital out of state. This cross-border communication has improved our ability to serve families.

An additional piece of the follow-up system has been added in recent months. Iowa is notifying families and physicians of children's risk factors for late onset or progressive hearing loss. This process had been on hold for a short time so that EHDI staff could educate physicians about risk factors and the reason additional audiological evaluations are needed. The process resumed in the fall.

Quality Assurance - Many steps have been taken to address quality assurance at the local and state level. Many hospitals have implemented procedures to ensure that all babies are entered into the eSP data system and that data are correct. The EHDI program also reviews data to be sure they are correct. This includes merging duplicate records, matching with birth certificate data to make sure all babies are accounted for, and searching for and marking deceased babies to avoid follow-up with their families.

At the system level, the Iowa EHDI Advisory Committee formed a quality assurance subcommittee. This subcommittee has developed a best practice manual which is expected to be available later this year. The EHDI Advisory Committee has also approved three protocols (newborn hearing screening, diagnostic assessment and high

risk infant monitoring) to guide the work of the EHDI system.

Education - The EHDI program has worked to educate everyone involved with EHDI about activities and best practice. The newsletter is once again being published on a quarterly basis. The EHDI brochure was also revised and reprinted in English and Spanish. The EHDI Web site has been revised with new information being added often. The EHDI Coordinator has also communicated with providers of hearing services regarding their roles and responsibilities in the EHDI program.

Funding - The EHDI program is funded by two grants; one is from the Centers for Disease Control and Prevention (CDC) and the other is from the Health Resources and Services Administration (HRSA). Both of the grants were recently renewed for a three year period through 2011.

The Iowa legislature has also appropriated funds for hearing aids and audiological services for children. The funding has been available since early 2008, and has been used by many Iowa families. IDPH receives the funding and works with a claims processor to get payment to providers.

Foreseeable Improvements

Screening and Reporting - Improvements to the data system are in process. This includes a revision of the audiological assessment section of eSP. This revision is expected to simplify entry of audiological evaluation results.

In the future, EHDI program staff would like to have a more comprehensive data system. This would include a stronger case management component within the data system. This is a long term goal.

Integration with other data systems is another long term goal of the EHDI program. The EHDI program has been exploring ways to integrate with other data systems to avoid duplicate entry on the local level, expedite follow up and ensure coordination with early intervention and family support programs.

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Hayden Sollars Invents "The Clip-o-Nator"

The EHDI program is always looking for articles to include in the quarterly newsletter regarding personal experiences regarding newborn hearing screening, diagnosis or follow up, best practices in hospitals, AEAs or audiology clinics, research or information about resources for parents and professionals. A couple of months ago, an EHDI Advisory Committee Member told us about Hayden Sollars and his invention so we tracked Hayden down and he gave us permission to share his story. Enjoy!

Hello my name is Hayden Sollars and I am a 5th grader at Cody Elementary. My invention is the "The Clip-O-Nator."

For many kids like myself wearing a hearing aid is a great responsibility. The toughest part for me was keeping track of it while playing sports, playing on the computer or just listening to my I Pod. Even when it was attached to my shirt with a string and clip the string was too long and other kids would get their hands caught in it while playing outside and the designs on all the clips were too babyish. Now with the Clip-o-Nator, I can select the length to fit my activity. For example, a shorter string for playing sports or a longer string for listening to my I Pod. I have also come up with new and cool designs for boys and girls that can be attached and reattached to the clip.

You might ask yourself, how does this help? The invention saves your child time from looking around for their hearing aid. It should also save money because your child shouldn't lose or hurt the hearing aid. It will also help while on the playground from accidental tangles with other kids.

How did I design this device? I took a badge clip with a retractable string and added Velcro for designs and a weight stopper. The weight stopper allowed me to adjust my string to a comfortable length and then I added my cool designs. I cut designs from fun foam and found other objects and stuck Velcro on the backs of the designs and the clip so they would stick.

The Web site I visited to help me get started on my invention was Inventiowa.org and uspto.gov/go/kids. The Invent Iowa Web site put me on the right track to see if anybody has patented my idea. Good news! I found no patents.



Hayden at State with his invention



Hayden wearing his invention

Iowa EHDI Program... Moving Forward!

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Referral and Follow-up, Family Support -

The EHDI program will be working with all partners to reduce the number of children that do not receive the follow-up they need. EHDI staff members will be looking at ways to reduce loss to follow-up such as: getting two points of contact for families, scheduling rescreen appointments before hospital discharge, collecting data on barriers to follow-up, etc. The EHDI program will also look to decrease the amount of time before the initial referral for follow-up is made to Early ACCESS for children who were missed or who referred and have not returned for a re-screen. The pilot for this effort will begin in December 08 or January 09. In addition, the EHDI program can compare records to other IDPH data systems in an attempt to locate families and physicians.

The 2007 Joint Committee on Infant Hearing Position Statement recommends that only AABR screening is used in the NICU. It also recommends that a baby in any nursery who does not pass an AABR screening should be rescreened using AABR. This practice is recommended so that auditory neuropathy/auditory dyssynchrony can be identified. The EHDI program currently makes referrals for follow-up on the newborn hearing screening and risk factors. The EHDI staff plans to expand follow-up to include diagnostic evaluation and entry into early intervention. This will require close communication with audiologists and early intervention professionals.

Family support programs will be expanded over the coming years. The Guide By Your Side (GBYS) family support program has been available since April 2007. The EHDI staff will be working to increase usage of the GBYS program and other family support programs. In addition, the EHDI staff will work to coordinate the efforts of various family support organizations across Iowa.

Quality Assurance - The EHDI staff will be visiting hospitals to review newborn hearing screening programs. These visits will be a chance to discuss compliance with the EHDI law, program quality,

hospitals' best practices that could be useful in other facilities, reducing the number of children lost to follow-up, and the family perspective on newborn hearing screening. All hospitals will be visited; visits are not based on program quality. Visits will begin in late 2008 or early 2009. The EHDI staff will then visit the Area Education Agencies and private practices who serve large numbers of children. The goals are to improve quality, consistency, and timely follow up.

The EHDI program will be working toward a comprehensive evaluation of the entire EHDI system including data system analysis and review of program indicators. The evaluation will be done by someone outside the system, allowing an objective view. Data are and will continue to be used whenever possible to drive program decisions and greater focus will be placed on data analysis in the coming year.

Education - The EHDI follow-up and family support coordinators will be visiting each AEA in the coming months. These visits will focus on EHDI referrals for Early ACCESS pre-service coordination, the follow-up process, GBYS, and other family support for families of children with hearing loss.

Update trainings will be made available. These trainings will be available to new and current users of eSP and will cover eSP and/or the EHDI program.

The EHDI program staff will also be working to reach communities that tend to refuse the newborn hearing screening. For example, in some parts of the state Amish families often refuse the newborn hearing screening at the hospital. EHDI staff members will work with community leaders to determine the best way to increase screening rates. Other communities that are identified as having a high refusal rate or low screening or follow-up rates will also be considered.

The EHDI program has made a lot of progress in the last two and a half years. Thank you to all of you who are committed to improving and building a comprehensive, coordinated EHDI system!

The Importance of Following Babies with High Risk Factors for Delayed Onset Hearing Loss



There are some health conditions or medical history factors that put a baby at particular risk for delayed onset hearing loss. These babies will often pass the newborn hearing screen, but develop significant permanent hearing loss in the first few months or years of life. Parents and primary care providers may even disregard their own concerns about hearing because the baby passed the newborn screen. In their 2007 position statement, the Joint Committee on Infant Hearing recommended that these risk factors be tracked and that babies at high risk for developing hearing loss receive an audiological evaluation later, with the recommended schedule based on the particular risk factor the baby has. (Other articles about the importance of reporting risk factors and recommended follow-up procedures can be found in the Spring 2008 and Summer 2008 editions of the Iowa EHDI news.)

One case in Iowa recently illustrates the importance of these follow up procedures. A 3 ½ year-old child was referred for concerns about behavior and speech and language delay. He had passed his newborn hearing screen in both ears, but had had significant behavior problems since infancy and severe speech

and language delay. He had been diagnosed by a local psychiatrist with attention deficit hyperactivity disorder (ADHD). Despite having a strong family history of sensorineural hearing loss, in every generation, and some physical findings at birth consistent with permanent hearing loss, it was not until after age three that he was referred for an audiological evaluation. After inconclusive behavioral audiological findings, an Auditory Brainstem Response (ABR) test indicated moderate hearing loss in both ears. He is being fitted with binaural hearing aids. There is no way to know when the hearing loss had its onset, but speech and language delay would suggest it was very early. If his risk factors had been reported in the EHDI database, effective intervention may have started earlier.

Best of Luck...

The EHDI program would like to extend our heartfelt thanks to Jeremy Miller for his tireless work behind the scenes of the EHDI program.



Jeremy has worked as an emergency employee and intern over the last two years. First it was data entry, then he assisted with training hospital personnel across the state in using eSP (eSCREENER Plus) and finally helping to implement quality assurance reviews in eSP. His smile and sense of humor will be missed as Jeremy exits left with a goal of landing a job in environmental or public health.

Contact Information

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**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.