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When Diagnostics Identify Early Hearing Loss

The purpose of newborn hearing screening is to identify children with hearing loss at the earliest age possible. In doing this, children can access communication through ASL, total communication, cued speech or an auditory-verbal modality; whatever the family decides works best for them. The longer a child goes without the family knowing that there is a hearing loss, the further behind they will be in learning to communicate. I have personally witnessed age of identification of hearing loss decrease dramatically over the last 20 years. Newborn hearing screening is the primary reason for this decrease.

When a hearing screening is completed in the hospital and a baby does not pass, all that is known at that time is that the baby did not pass. Many reasons exist for this result, including middle ear fluid, birthing debris in the ear canal, an uncooperative baby and/or hearing loss. A follow-up hearing screen should be completed

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Advisory Update

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

January 6, 2011

9 a.m. - 12 p.m., ICN, contact EHDI coordinator for more information

January 2011						
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Contact Tammy O'Hollearn for special accommodations at least 48 hours in advance of the meeting

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

When Diagnostics Identify Early Hearing Loss

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within two weeks and at that time if the baby does not pass again, a 1000 Hz tympanogram can help to identify if middle ear issues could be a contributing factor in a baby not passing their hearing screen. Should a baby have a non-passing hearing screen at this time and a normal high-frequency tympanogram, a diagnostic ABR should be scheduled.



An Auditory Brainstem Evoked Response (ABR) test can test the brain's response to sound at several different frequencies and different loudness levels. This will confirm whether a child has hearing loss and whether it is something that will require hearing aids, audiological monitoring or both. When hearing loss is identified, and the hearing loss is sensorineural or permanent hearing loss, delivering that news to parents is always quite difficult.

Even if parents have some idea that their child is not hearing well, telling the parents that their fears are confirmed and that a significant hearing loss is present is often met with tears and even anger. At the time of delivering this news, the basics are addressed. What is the level of hearing loss, what does this mean for the child and what are the next steps? Usually anything more than this information is not able to be processed well by the family at that time. I have found that a more detailed explanation at a later date using a familiar sounds audiogram; the EMDI Resource Manual; and other handouts help parents understand the hearing loss and its implications. Referring the child to the Early ACCESS (early intervention) program through their local Area Education Agency is imperative and referring them to the Guide by Your Side (family support program for parents of children who are deaf or hard of hearing) has also proven to be helpful for families. A referral to an Ear, Nose and Throat physician (ENT) is often made shortly after the ABR if the family was not already connected with this specialist.

Overall, telling a family that a child has hearing loss is never an easy thing. But with the resources now available in print and in the people that will work with the child, it has certainly been made easier. I have found that even if a family initially has difficulty accepting the information, with reassurance and patience, usually they will accept the situation they are in and do everything they can to help their child in a way that meets the needs of the child and family.

By Diana Hanson, MS, CCC-A

Iowa Symposium on Hearing Loss

On September 17 and 18, 2010, professionals and families gathered in Ankeny to participate in the 2010 Iowa Symposium on Childhood Hearing Loss. Attendance of 112 was an all-time high. Speakers included Dr. Marilyn Neault, from Boston Children's Hospital, who gave an excellent presentation on auditory neuropathy/dyssynchrony. Dr. William Kimberling and our own Dr. Jeanne Prickett gave a joint presentation on medical and educational implications of Usher Syndrome. This session was enhanced by comments from our keynote speaker, Brian Grubb, an inspirational man who is deaf and blind from Usher Syndrome. Mr. Grubb gave an insightful and humorous presentation during the dinner hour. Leeanne Seaver from national Hands and Voices provided helpful suggestions for parents with respect to sibling relationships and communication considerations for children.



Attendees also heard from Iowa speakers about current Iowa EHDI data, the Iowa Medical Home Initiative, and current research in outcomes for children who are hard-of-hearing, FM amplification, assistive devices and behavior management strategies. The screening lab session for nurses and panel presentations by parents of children who are deaf or hard-of-hearing and young adults who are deaf or hard-of-hearing were very well received. The two days in September provided a wonderful, relaxed networking opportunity for all Iowa EHDI stakeholders. Evaluations by participants indicated this was the best Iowa EHDI conference ever. If you or a colleague has suggestions for keynote speakers or sessions for 2012, please contact Lenore Holte at lenore-holte@uiowa.edu or call (319) 356-1168. We thank everyone for their participation and help and look forward to seeing everyone again in 2012!

Ear, Nose and Throat Clinic Opens in Council Bluffs

A new Ear, Nose and Throat Clinic opened in Council Bluffs and will serve Council Bluffs and the neighboring communities. The clinic is located at 320 McKenzie Avenue. The clinic, affiliated with Boys Town National Research Hospital, will offer pediatric and adult medical care for simple to complex ear, nose and throat conditions. The clinic also includes a center for hearing evaluations which includes high frequency tymps, OAEs, VRA, CPA and conventional audiograms, as well as hearing aid technologies. Board certified physicians at the clinic include Michael Crawford, MD and Rodney Lusk, MD.

Clinic hours are Monday through Friday, 8 a.m. - 5 p.m. To schedule an appointment at the Ear, Nose and Throat Clinic, call (712) 256-5272. For more information on services available at the clinic, visit 'Patient Services' at www.boystownhospital.org.

Amplification Makes a Difference ... One Child's Story

Children who are deaf or hard-of-hearing not only have difficulty hearing soft speech, but also have relatively more difficulty understanding speech in noisy environments than do their normal-hearing peers. Many children who use amplification also use special devices in the classroom, usually FM systems, that improve what audiologists call the "signal-to-noise ratio." These devices require the teacher to wear a microphone and amplify only the teacher's speech and not the background noise. In Iowa, FM systems are primarily only used in classrooms and few children get the benefit of this kind of amplification in other environments. One Iowa family noticed a big difference in their daughter's ability to understand in school with the FM system relative to her ability at home without it. Their audiologist asked for special approval for Medicaid to cover an FM system for home and family use. Approval took a long time, but was finally received, and the results have been amazing. Below is a note from her mother, thanking everyone for the approval of this technology for her daughter.



A photo of Brianna

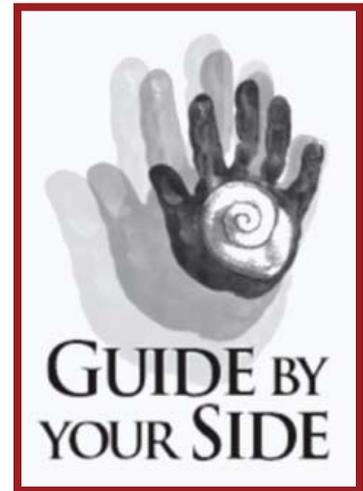
"Our daughter, Brianna, has a moderate-severe hearing loss in both ears and has had hearing aids since age one. Brianna also has Down syndrome. We recently received approval for an at-home FM system for Brianna through Medicaid. She had been using an FM system at school through preschool and kindergarten and had become so used to using the FM system at school this past year that she began refusing to wear her hearing aids without the FM system at home. She would sign to us that the aids were broken. All of our tricks to get her to wear her hearing aids were no longer working. We spoke with her audiologist and after a great deal of work; we finally got an FM system for home. When we got the new at-home FM system, we still struggled to get Brianna to put the aids on. Finally, with the help of Curious George, we were successful. Brianna got a look of delight on her face, started jumping up and down and signing "fix." She has since signed to have her "new hearing aids - fix" put on at home. She makes sure her therapists get the microphone right away and she loves to hear her grandparent's voices as well as ours and her sister's. She makes sure each of us get a turn. We are THRILLED! We are very grateful for the approval of the FM system. We feel - and her therapists agree - that this will make a HUGE impact for Brianna. We are already seeing good things happen for her. We are excited to continue to see changes in her with this new at-home FM system. Thank you Medicaid for providing her this opportunity."

"We feel - and her therapists agree - that this will make a HUGE impact for Brianna. We are already seeing good things happen for her."

By Sara Kelley, parent and Lenore Holte, PhD, Lead EHDI Audiologist

Guide by Your Side Program Making Strides

Vicki Hunting, CHSC Project Director, and Susan Hagarty, Guide By Your Side Program Coordinator, gathered their team at the Iowa Symposium on Childhood Hearing Loss in September. Five parent guides met to share insight, complete training and to get to know each other better. Guides in attendance included Arlys Jorgenson, Anne Hender-Jasper, Amy Pettit, Brandi Nielson and Calley Welch.



Leanne Seaver, Executive Director of Hands & Voices National welcomed the guides personally as they began their post-conference extended training on Saturday afternoon.

Hagarty is pleased with the skills and knowledge the parent guides bring to our parent support program. She adds, "We are ready to roll when the referrals roll in."

Referrals to the program have increased dramatically, but not at the rate Hagarty and Hunting would like to see.

Other short term goals for the program include hiring a Hispanic guide or consultant and connecting current guides with diagnostic center staff across the state.

Members of the Guide By Your Side team will continue to organize informational sessions with AEA staff, attend hospital site visits and connect monthly to share resources.

By Susan Hagarty, Family Support Coordinator



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

Hearing Aid Funding **Makes a Difference**

The Early Hearing Detection & Intervention (EHDI) program is a source of funding support for families of children with hearing loss in need of hearing aids whose insurance does not cover the costs. The funding was made possible through an appropriation to the Iowa Department of Public Health by the Iowa legislature. The intent of the funding is to provide payment for hearing aids and/or audiological services for children whose private insurance does not cover the costs and who would otherwise not be able to afford these services. An application and "Frequently Asked Question" sheet are available on the EHDI program website under the 'Parents' or 'Professionals' pages at www.idph.state.ia.us/iaehdi/default.asp. You can also contact Vickie Miltenberger for more details and an electronic or mailed copy of the application at 1-800-547-6789. Following is a family story submitted by Shelli Blazic. She and her husband worked with EHDI to receive funding to purchase new hearing aids and an FM system for their daughter.

"Our daughter Josephine was born with bilateral hearing loss and received her first set of hearing aids at three months of age. It was at that time we became aware of a world of resources we would not otherwise have a need for. Like most families in similar circumstances we quickly discovered that hearing aids and other audiological necessities were not covered under our private insurance. While we had the financial resources at the time and were also blessed that there were no other outstanding medical needs for Josephine, paying out-of-pocket for all of the intensive services she needed created a financial strain on our family.



A photo of Josephine

The staff at Great Prairie AEA were instrumental in offering information about the EHDI program and assisting us with navigating the process. The team at Wendell Johnson Speech & Hearing Clinic offered support in filling out the application, setting up appointments and getting Josephine her equipment in a timely manner.

We are so appreciative of the collaboration of services that Josephine has received. It takes each entity working collectively to meet the needs of an individual child. Without the awareness of the EHDI program, we might still be searching for a way to optimize hearing for our daughter. With the assistance of the funding for new hearing aids and an FM system for Josephine, we have the peace of knowing that her time in the preschool classroom and at home affords her greater and more meaningful opportunities for hearing, learning and interacting with family and friends."

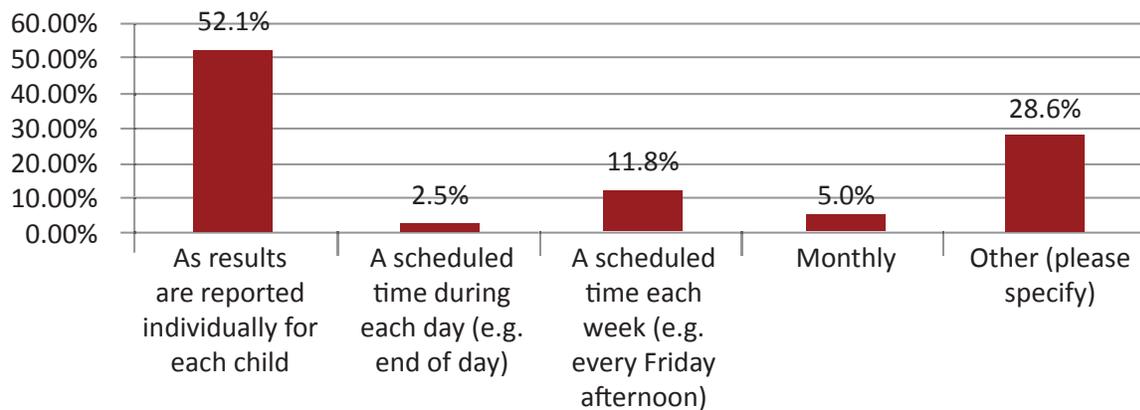
By Shelli Blazic, parent

Results from the Surveillance Survey

First, thanks to all of you who participated in our surveillance survey! Your feedback will help to improve the EHDI program.

The EHDI program sent out a surveillance survey about our web-based data system, eSP. This survey was completed by 128 individuals from birthing hospitals and Area Education Agencies. Surveys were completed from September 10 - October 1, 2010. Seventy percent of respondents were from birthing facilities and 27 percent were from AEAs. Of the respondents from birth hospitals, 52 percent were from level 1 hospitals, 25 percent were from level 2 and 7 percent were from level 3 hospitals. Seventy percent of birthing hospital respondents indicated that they did not have a NICU or specialty nursery. Ninety-one percent of respondents indicated that their skill level was intermediate to advanced.

When are the results entered into the EHDI data system



Over half, (52 percent), of respondents indicated that results are entered into eSP individually for each child. However, 5 percent of respondents indicated that results are entered monthly at their facility. This 5 percent of facilities are not meeting the six day timeframe required by law for reporting hearing screening and assessment results. Eighty-five percent of facility data is entered daily or weekly. Sixty-three percent of individual data is entered daily or weekly. Results are entered at various times depending on the facility. Many of those that indicated 'other' were entering results multiple times a week or whenever time allowed.

Among respondents who indicated they used the eSP functions; those functions that are used most frequently are: adding/editing patients, demographics, risk factors; patient searches; adding/editing assessment results; and letters. Functions that are not used regularly would include adding/editing amplification and intervention results; appointment scheduling; adding/viewing patient case notes; and the birth admission screening, follow up screening, and aging reports. Overall, 80 percent of respondents strongly agreed or agreed that eSP was easy to use.

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Results from the Surveillance Survey

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The EHDI program continues to focus on quality assurance activities to help ensure accurate and complete data entry. Survey results indicate that among birthing hospital respondents, 53 percent of respondents routinely monitor their miss and refer rates and only 36 percent use the birth admission screening and follow up screening reports to track these rates. Of AEA respondents, 55 percent compare their referral lists to ensure all results are entered into eSP.

Respondents indicated that 47 percent of new employees are trained by facility staff and 82 percent would participate in additional training if it were offered, preferably by EHDI staff. Sixty-two percent of respondents strongly agree or agree that the training material is easy to understand and follow.

Additional analyses will be completed among all respondents and also by facility type. These results will be presented to the EHDI Advisory Committee and available by request. The EHDI team will also talk with our vendor to identify suggestions regarding functionality that can be incorporated into eSP. Some comments highlighted the need for additional trainings versus a change in functionality. EHDI staff will look into the possibility of having regional trainings across Iowa to retrain facility staff, provide tips for data entry and discuss the importance of quality assurance checks.

A few respondents had questions or concerns about how to use certain functions or reports in eSP. However, EHDI staff are unable to answer these due to anonymity of the survey responses. EHDI staff are always available through phone or e-mail to answer any questions or concerns related to the use or functionality of the eSP data system. Contact Jen Thorud, EHDI program evaluator at (515) 281-0219, jthorud@idph.state.ia.us or Tammy O'Hollearn, state EHDI coordinator at (515) 242-5639, tohollea@idph.state.ia.us with any questions.

Thanks again to everyone who participated; your feedback and suggestions help improve the EHDI program!

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:

Hearing Equipment Coordinator –
(800) 272-7713

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

2010 Hearing Aid & Audiological Services Legislative Update

During the 2010 Iowa legislative session, the issue of hearing aids and audiological services for children came up several times. Early on in the session, a bill came before a subcommittee of the House Commerce Committee, HSB 223. This bill required private insurance plans, which are regulated by the Iowa Insurance Commissioner, to cover audiological services and hearing aids for children. Currently, families with private health care coverage usually have no coverage for those needs for their children who are hard-of-hearing or deaf.

The subcommittee was an exciting one with many attendees there in support of the bill, including three families who told their personal stories. We can't thank them enough for taking off of work, traveling to Des Moines and sharing their stories. The subcommittee voted the bill out of committee and it became eligible to be debated in the Commerce Committee. However, due to lack of support for passage of the bill in Commerce by a majority of members, the bill never came up for a vote in that committee.

Shortly after that bill died, another bill came up from the House Human Resources Committee, HSB 682. That bill essentially matched the first bill and included a mandate for private insurers to cover audiological services and hearing aids for children. Another exciting subcommittee was held, this one even bigger than the first! Several families attended and children with hearing aids spoke on their own behalf. The bill made it out of subcommittee and a couple weeks later was voted out of the Human Resources Committee on a party line vote. The Democrats voted unanimously to support the bill and the Republicans voted unanimously against it. Representative Janet Petersen (D - Des Moines) was the lead on the bill and worked on it in both subcommittees and committees. Representatives Tyler Olson (D - Cedar Rapids) and Mark Smith (D - Marshalltown) were also strong supporters of the bill and helped move it through.

And then, we waited. We waited and waited for the bill to come up on the debate calendar for a floor debate and vote in the House. It never came up. Many supporters sent in e-mails and made phone calls to legislators asking for a floor vote, but we did not prevail. The bill languished until the end of the session on March 30th, and then died.

The final outcome to the legislation was very disappointing and many of us wish it had come out differently. If such legislation comes up again this year, the Child and Family Policy Center will support it. We also continue to bring this issue up at the federal level and want it included in additional health care reform legislation.

By Carrie Fitzgerald, Senior Health Policy Associate, Child and Family Policy Center

Hearing Health: The Importance of the Medical Home

Hearing screening within the medical home is important if infants with hearing loss are identified early and receive the optimal benefit of available technology and intervention. One of the early functions of the medical home is to ensure that all hospitals and birthing centers in their community of practice provide hearing screening using a physiological measure before one month of age. They should also promote the identification of the pediatric medical home for all newborn infants by the time of discharge from the birthing facility.

Primary care providers have regular contact with children and their families during the first three years of life. Thus they have an excellent opportunity to monitor speech and language at each well child visit.

Population studies show that the prevalence of permanent hearing loss increases as children age as a result of delayed onset hearing loss and acquired hearing losses. It is important that parents and physicians continue to be vigilant about the child's hearing even when they have passed the newborn hearing screen. The Joint Committee on Infant Hearing Surveillance Recommendations in the

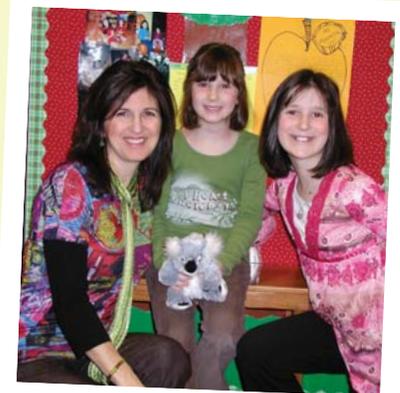
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Welcome Michelle Vaccaro - Newest EHDI Advisory Committee Member

Michelle Vaccaro recently joined the EHDI Advisory Committee as a parent representative. She has two daughters, the youngest of which has a moderate-severe hearing loss and, uses hearing aids and an interpreter full time at school. Michelle reports using American Sign Language (ASL) and Pidgin Sign(ed) English (PSE) in the home in addition to speech since Jordan's birth. Michelle fully supports ANY mode of visual communication which can aid the child's overall learning and development.

Michelle says she and her family are fortunate to have had the support and influence of Jordan's father, who is deaf and from a deaf family. His family is strongly connected to the deaf community in the Washington, D.C. area, from where they moved in 2002. According to Michelle, they all continue to broaden her understanding and appreciation of deaf language and culture.

Michelle and her daughters live in Ankeny where she works as a professional counselor for Des Moines Area Community College. Her work has helped her to stay connected with her passion of student advocacy and disability services. In addition, Michelle has also served on the Iowa Hands & Voices board for the last several years. Michelle and her family enjoy many outdoor activities like hiking and sailing, in addition to cooking and crafting. Welcome Michelle!



Michelle Vaccaro and her two daughters

Hearing Health: The Importance of the Medical Home

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Medical Home for infants who have passed the newborn hearing screen include frequent monitoring of all infants at visits consistent with the American Academy of Pediatric periodicity schedule. Infants should be screened for auditory skills, middle ear status and developmental milestones. Children with permanent middle ear effusion that last three months or longer should be referred for otologic evaluation. A validated global screening tool should be administered to all infant at nine, 18 and 24-30 months or if there is a physician or parental concern about hearing or language development. If the infant does not pass the speech language portion of a global screening tool in the medical home or if there is physician or caregiver concern about hearing, the child should be immediately referred for further evaluation by an audiologist and speech language pathologist.

Another important function of the medical home is that once hearing loss is diagnosed in an infant, siblings who are at increased risk of hearing loss should also be referred for audiologic evaluation. All infants with a risk factor for hearing loss, regardless of the surveillance findings, should be referred for repeat audiologic assessment at least once by 24-30 months of age. The AAP provides five strategies for comprehensive surveillance by pediatric medical home providers.

1. Medical home provider should provide parents with information about hearing, speech and language milestones.
2. They should identify and aggressively treat middle ear disease.
3. Provide vision screening and referral as needed. Children with hearing loss rely on vision to supplement what is heard. Monitoring vision health protects this vital sense.
4. Provide ongoing developmental surveillance and referral to the appropriate resources.
5. Identify and refer for audiologic monitoring infants with risk factors for late onset hearing loss.

It is the role of the medical home to identify these risk factors during well baby checks. The medical home primary care providers can realize a successful EHDI Medical Home in partnership with parents by achieving the following:

1. Screening newborn hearing no later than one month of age. Conducting diagnostic assessments no later than three months of age and if failed, ensuring an enrollment in early intervention program no later than six months of age.
2. Fitting with hearing aids within one month of confirmation of hearing loss. Monitor children with risk factors for late onset of progressive hearing loss and referring at-risk children regardless of hearing screening for at least one assessment at 24-30 months. Facilitate enrollment in early intervention programs. Examine and overcome management issues facing the medical home and carrying out the screening and intervention process.

Additionally the medical home can also facilitate referrals as well as coordinate evaluations by other medical specialties as needed. These may include genetics, ophthalmology and otolaryngology. The medical home can also be a resource for community-based support and advocacy.

Contact Information

State EHDI Coordinator

Tammy O'Hollearn
Iowa Department of Public Health
(515) 242-5639
tohollea@idph.state.ia.us

EHDI Follow-Up Coordinator

Peggy Swails
Child Health Specialty Clinics
(319) 356-3570
peggy-swails@uiowa.edu

Family Support Coordinator

Susan Hagarty
Child Health Specialty Clinics
(866) 219-9119
susan-hagarty@uiowa.edu

Audiology Technical Assistance

Lenore Holte, Ph.D.
University of Iowa Hospitals and Clinics
Center for Disabilities and Development
(319) 356-1168
lenore-holte@uiowa.edu

Nick Salmon
University of Iowa Hospitals and Clinics
Center for Disabilities and Development
(515) 576-5312
nsalmon@frontiernet.net

Emily Andrews
University of Iowa Hospitals and Clinics
Center for Disabilities and Development
(319) 384-6894
emily-andrews@uiowa.edu

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

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

Tammy O'Hollearn, Iowa EHDI Coordinator
Iowa Department of Public Health
321 E. 12th Street
Lucas Building - 5th Floor
Des Moines, IA 50319
Phone: (515) 242-5639
E-mail: tohollea@idph.state.ia.us

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