



## Researchers Awarded Funding to Study Outcomes of Children with Hearing Loss

### What's inside...

- P1-2** Research Awarded Funding to Study Outcomes of Children with Hearing Loss
- P2** Looking for a Few Good People
- P2** Area Education Agency Visits
- P3** Primary Contact - Required Field by Law
- P3&5** Friendly Reminders
- P4** Thank You!
- P4** Welcome Melissa
- P5** Hearing Aids & Audiological Services Funding
- P5** EHDI Prenatal Education Materials
- P6-7** EHDI Progress - We've Come A Long Way!



Thanks to newborn hearing screening, hearing loss can now be identified very early in life. Early detection can prevent or reduce delays in children's speech and language development. However, more research is needed to determine if this goal is being achieved for the majority of infants who are hard-of-hearing. In addition, some cases of hearing loss, especially mild hearing loss, go undetected, even with newborn hearing screening.

Research is also needed to better understand the unique needs of these children. Few studies have explored the needs of children who use hearing aids and have mild-to-severe degrees of hearing loss. The National Institute on Deafness and Other Communication Disorders (NIDCD) recognized the need to fill this gap so that interventions for these children can be strengthened. With new funding from this agency, researchers at the Universities of Iowa, Kansas, North Carolina and Boys Town National Research Hospital in Omaha are working together to understand the successes and needs of children with mild-to-severe hearing loss and their families.

*continued on page 2*

## Advisory Update

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

**January 8, 2009 - ICN**

If you wish to attend, contact Tammy O'Hollearn (contact information on back of newsletter).

January						
S	M	T	W	T	F	S
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

**Past meeting agendas, minutes and a list of committee members are available online! Visit [www.idph.state.ia.us/iaehdi](http://www.idph.state.ia.us/iaehdi).**

# Researchers Awarded Funding to Study Outcomes of Children with Hearing Loss

*continued from page 1*

The group is looking for children and families to participate in this research. They seek children with confirmed mild-to-severe hearing loss, ages six months to six years. Once enrolled in the study, the children will be tested at least once a year for three consecutive years. Parents will be interviewed and teachers will be asked to complete surveys between the testing visits. All the testers will strive to make the testing fun for participants. Testing will be held in the child's community as much as possible. Anyone wanting more information about this study can contact Marlea O'Brien at [marlea-obrien@uiowa.edu](mailto:marlea-obrien@uiowa.edu) or (800) 551-5601.

## Looking for a Few Good People!

The Iowa Department of Public Health EHDI program is looking for a hospital nurse that works with the Iowa EHDI program, an otolaryngologist, parents of children with hearing loss and adults who are deaf or hard-of-hearing to serve on the EHDI Advisory Committee. The committee meets quarterly (January, April, July and October). Meetings are held in Des Moines from 10-3 p.m. We want to increase membership and ensure we have representatives from the various disciplines we work with, as well as parents and consumers. If you are interested in becoming a member, please contact Tammy O'Hollearn at [tohollea@idph.state.ia.us](mailto:tohollea@idph.state.ia.us) or call (800) 383-3826.



## Area Education Agency Visits

In the next six months, Erin Kongshaug, Melissa Carlson and Guide By Your Side (GBYS) guides will be visiting each Area Education Agency (AEA). These visits will be a chance to talk to Early ACCESS and AEA staff members in each part of the state about family support for families of children with hearing loss. We will also discuss the process for referrals to Early ACCESS from the EHDI program.

Erin will be in touch with each AEA to schedule these visits. If you'd like to volunteer to be one of the first, or if you have a particular date that would work for your AEA, please contact Erin.

# Primary Contact - Required Field by Law

Through recent quality assurance checks, the EHDI program found that some hospitals left the primary contact field blank. The name, address, and telephone number of the mother of the newborn, if available, is required by law. If the birth mother is not the person designated as legally responsible for the child's care, the name, address and telephone number of the parent, as defined below shall be reported:

"Parent" means:

1. A biological or adoptive parent of a child;
2. A guardian, but not the state if the child is a ward of the state;
3. A person acting in the place of a parent, such as a grandparent or stepparent with whom a child lives, or a person who is legally responsible for the child's welfare;
4. A surrogate parent who has been assigned in accordance with 281-120.68(34CFR303); or
5. A foster parent, if:
  - A biological parent's authority to make the decisions required of parents under state law has been terminated; and
  - The foster parent has an ongoing, long-term parental relationship with the child; is willing to make the decisions required of a parent; and has no interest that would conflict with the interests of the child.

If mother is not the primary contact for the child, please enter mother's contact information and deselect "primary contact" and "send letters." Then you may go back in and add the primary contact under another alias (e.g., Lutheran Social Services, Polk County DHS, etc.). In addition, case notes are very helpful for follow-up when there are extenuating circumstances requiring sensitivity.

## Friendly Reminders

- 1 Please mark applicable risk factors for all children.** If a child does not have risk factors, click on the "edit risk factors" tab, click on "select all to no" and save.
- 2 Please choose the risk factor NICU greater than 5 days when applicable.** The EHDI program is notifying parents and the PCP/medical home to provide instructions regarding recommended follow-up for children with risk factors associated with hearing loss.
- 3 The receiving hospital is responsible for completion of the newborn hearing screen.**
- 4 Search for all children who are transferred to your hospital from another facility.** Do not automatically enter them into the system. If you cannot locate the child, contact the birthing hospital to enter and transfer the child to your facility or the EHDI program staff for further assistance.
- 5 Make sure you enter the physician that will be following-up with the child upon discharge from the hospital.** This helps the EHDI program complete timely follow up with the physician for children with risk factors or those children who were missed or referred and have not returned for a rescreen.

*continued on page 5*

# Thank You!

The EHDI program would like to give our heartfelt thanks to Vicki Hunting and Cami Wright for their work as parent consultants. Vicki and Cami are mothers of children with hearing loss and were instrumental in bringing Hands & Voices (H&V) and Guide By Your Side (GBYS) to Iowa. Both have given their time generously to make sure that Iowa families are represented in the activities of the EHDI program. Their input and hard work have made Iowa a better place for children with a hearing loss and their families.

Cami has left the EHDI program so she can focus more energy on her family and nursing career. She will continue to be involved in Iowa H&V.

Vicki has turned the GBYS program over to Melissa Carlson so that she can devote more time to her role as co-president of Iowa Hands & Voices. In that role, she will remain involved with GBYS providing oversight, support and advice from the H&V perspective.

Thanks again to both Vicki and Cami for their dedication to Iowa families.

---

## Welcome Melissa!

The Iowa EHDI program would like to welcome Melissa Carlson, our new family support coordinator. Melissa works out of the Child Health Specialty Clinics office in Iowa City, and splits her time between EHDI and Early ACCESS duties. For the EHDI program, she is managing the Guide by Your Side program and coordinating the other family support activities of the HRSA grant.

Melissa earned her undergraduate degree from the University of Iowa and her masters in speech-language pathology from the University of North Carolina - Chapel Hill. She worked as a speech language pathologist and Montessori preschool teacher for 20 years.

Melissa and her husband have three children. Their youngest, Julia, has moderate hearing loss and wears hearing aids.

We are glad to have Melissa on board. If you have questions for her, she can be reached at (319) 353-7389 or [melissa-carlson@uiowa.edu](mailto:melissa-carlson@uiowa.edu).



**Back row (left to right):** Melissa Carlson and Kathy Miller

**Front row (left to right):** Amy Pettit, Anne Hender and Arlys Jorgensen

# Hearing Aids & Audiological Services Funding...

## First Year in Review

In a period of five months ending June 30, 2008, \$131,672.55 was paid to Iowa providers for children in need of hearing aids and audiological services. At least another \$15,000.00 is currently being processed for that same time period.

Funding was made possible by the legislature in the 2007 session to cover uninsured or underinsured Iowa children in need of hearing aids or audiological services. The following is a breakdown of the net averages for the claim payment statistics.

Number of claims processed	119
Total dollars paid	\$131,672.55
Number of children with one paid claim	92
Average number of claims per child	1.3
Average paid per child	\$1,431.22
Average paid per claim	\$1,106.49

\$78,000 dollars was used to cover the costs of hearing aids. Additional funding was used for batteries, ear molds, FM systems, assessment, and dispensing/fitting fees. There were a few children enrolled in the program that did not access services by June 30th because of scheduling conflicts, etc. Those children were re-enrolled and are being served in the second year.

The second year of funding began on July 1, 2008, and there are 71 children currently enrolled in the program. There have been 28 claims paid this year for a total of \$19,109.00, and the program has another seven claims pending for approximately \$6,500.00.

## Friendly Reminders

*continued from page 2*

**6 Do not let the language default to English for families that require follow-up in Spanish or another language.** This causes further delays in getting children back in for a rescreen in a timely manner.

**7 Hospitals should have a refer rate of eight percent or less and a miss rate of no more than one percent.** Within the next year, the refer rate will decrease to no more than six percent. If your refer rate is currently above eight percent, please work with your assigned audiology technical assistant to explore strategies to reduce your refer rate.

**The following links may be useful for hearing screen coding for primary care providers:**

Hearing Screening Coding Fact Sheet for Primary Care Providers-AAP Web site:

[www.medicalhomeinfo.org/screening/EHDI/EHDI%20info%20for%20providers/EHDI\\_Coding\\_Fact\\_Sheet\\_FINAL.pdf](http://www.medicalhomeinfo.org/screening/EHDI/EHDI%20info%20for%20providers/EHDI_Coding_Fact_Sheet_FINAL.pdf)

Denial Management and Negotiation Hearing Screening-AAP Web site:

[www.medicalhomeinfo.org/Screening/EHDI/EHDI%20info%20for%20providers/Appendix\\_A\\_FINAL.pdf](http://www.medicalhomeinfo.org/Screening/EHDI/EHDI%20info%20for%20providers/Appendix_A_FINAL.pdf)

# Standardizing the Follow-up Process

EHDI has been making formal referrals to Early ACCESS (Iowa's Part C-Early Intervention Program) since May of 2007. The referrals are for children still needing follow up due to a missed or referred (failed) newborn hearing screen. The referrals are sent to the Area Education Agencies (AEAs), grantees for the Early ACCESS (EA) program. Many AEAs pass the referrals along to their audiology departments because of their expertise and experience with hearing screening and follow up. The audiology departments then make several attempts to reach the family by phone, letter, or a combination of the two. Until now, there were many different procedures used throughout the state.

At the end of September, Tammy O'Hollearn, Iowa's EHDI Coordinator, met with members of the AEA Leadership Committee to discuss a recommendation by the EHDI Quality Assurance team to standardize referral procedures across the state. The Leadership Committee embraced the idea and the following procedures will be implemented in the coming months as best practice for EHDI referrals. These procedures will also be included in the EHDI Best Practices Manual due out this fall and the AEA policies and procedures manual currently in development.

1. The EHDI program will send electronic referrals to the EA Regional Liaison in each region once per month for infants who were missed or who referred (failed) on their newborn hearing screen and have not returned for a follow up screen.
2. Within 48 hours, EA will make an attempt to reach the family by phone. If no one answers and voice mail is available, EA will leave a message. If the phone has been disconnected, move directly to the 4th step below (mail a letter).
3. After 7-10 days, a second attempt to reach the family by phone will be made.
4. After 7-10 days, a final attempt will be made to reach the family through a written letter.
5. EA will notify the EHDI program if the attempts were unsuccessful and a case note will be made in the child's eSP record. EHDI staff members can be notified via:
  - EA-EHDI referral form
  - E-mail to EHDI Follow Up Coordinator or State EHDI Coordinator
  - Phone
6. The EHDI Follow Up Coordinator will make a final attempt to get the child in for follow up through a written letter to the child's primary care physician and family.

We want to thank the EHDI Quality Assurance Committee and the AEA Leadership Committee for their commitment to a consistent statewide procedure which will assist the EHDI program with timely follow up!

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

On September 19 and 20, professionals and families gathered at the Scheman Center in Ames for the Iowa Symposium on Hearing Loss: Impact on Children and Their Families. Attendees included nurses, audiologists, speech-language pathologists, itinerant teachers, early intervention specialists, parents, and adults with hearing loss. All attendees had the opportunity to hear national speakers and network informally during the two-day meeting.

Friday's sessions featured information on Reducing "Lost to Follow Up" in EHDI programs, the Deaf Children's Bill of Rights, Genetics of Childhood Hearing Loss and the Foundations for Literacy: Balancing Listening, Language & Sign. Saturday kicked off with a wonderful session on Audism. A quote from a participant summed the session up nicely, "this session served as a great reminder and opportunity to teach us "hearing" folks the life long impact our actions have on a child who is Deaf or hard-of-hearing." Afternoon sessions included Pediatric Hearing Aid Fitting and Verification, Optimizing Auditory Access: Strategies for Fostering Listening Skills, a Screening Lab for Nurses, Iowa EHDI – A Work in Progress, Resources for Parents Panel, High Risk Monitoring and the symposium ended with a Young Adults Panel.

The weather was beautiful and sessions educational. The conference planning committee received positive feedback and great suggestions for the next symposium. We look forward to seeing all of you in September 2010!

## EHDI Prenatal Education Materials

Before the end of the year, the EHDI program will be compiling prenatal education materials regarding newborn hearing screening. If you would like to make these materials available in your prenatal/childbirth education classes, please contact Erin Kongshaug. Contact information is available on the back cover.

## 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

## 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

Erin Kongshaug  
Child Health Specialty Clinics  
(515) 281-4653  
erin-kongshaug@uiowa.edu

### 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  
Early Hearing Detection and Intervention (EHDI) Program  
Iowa Department of Public Health  
321 E. 12th Street  
Lucas Building - 5th Floor  
Des Moines, IA 50319  
Phone: 1-800-383-3826  
E-mail: [tohollea@idph.state.ia.us](mailto:tohollea@idph.state.ia.us)

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