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Best Practice - Rescreen Both Ears

There has been some confusion among Iowa EhDI providers about recommended best practices for rescreening. Tammy O'Hollearn, our Iowa EhDI Coordinator, recently sent some questions to the members of the Joint Committee on Infant Hearing (JCIH) for clarification. The JCIH discussed her questions at their February meeting and we would like to share their recommendations.

Three scenarios were presented to the committee about re-screening both ears when an infant does not pass a screen in one ear.

1. Hospitals with a stage-two OAE/AABR screening protocol during the birth admission. When a baby fails an OAE screen in one ear and passes in the other, some hospitals have been doing the immediate AABR screen only in the ear that does not pass the OAE screen. JCIH advises to do the follow-up AABR screen in both ears.

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Advisory Update

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

July 7, 2011
10 a.m. - 3 p.m.,
Altoona Public Library

July 2011						
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						

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.

Best Practice - Rescreen Both Ears

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2. Hospital uses a two-stage OAE/AABR screen. The baby does not pass the OAE screen in one ear only and passes in the other. The AABR screen is performed in both ears. This time the baby does not pass the AABR screen in the ear that had passed OAE and passes the AABR screen in the ear that did not pass the OAE. This baby was labeled as a pass in both ears. The JCIH advises against this. The baby should be rescreened in both ears and a pass requires she pass in both ears
3. Baby does not pass initial OAE screen while in well baby nursery or AABR screen in NICU. Hospital personnel or audiologist only screens the ear the baby did not pass. The JCIH statement is clearest about this scenario and recommends rescreening in both ears.

In their February 19 discussion, the JCIH members unanimously agreed that all rescreening should include both ears on every rescreen and both ears would need to pass during the rescreening. These issues will be addressed in the next JCIH position statement so they are more clear.

By Lenore Holte, Ph.D., Lead EHDl Pediatric Audiologist

Purchasing New Screening Equipment?

If you are purchasing new screening equipment (OAE or AABR) now or you are planning for future needs, please visit the National Center for Hearing Assessment and Management website. The NCHAM recently posted a hearing screening equipment comparison chart, www.infanthearing.org/screening/equipment.html.

The EHDl team also encourages you to call one of our audiology technical assistants for information regarding the experiences of other Iowa hospitals with various screening equipment.

Emily Andrews, MA, CCC-A - Eastern half of Iowa (319) 384-6894

Nick Salmon, MS, CCC-A - Western half of Iowa (515) 576-5312

Lenore Holte, PhD, CCC-A - EHDl Lead Audiologist (319) 356-1168

Auditory Neuropathy/ Auditory Dyssynchrony in the News

Recently several of us on the Iowa EHDI staff and on the advisory committee were contacted about questions arising from an article on CNN's website (www.cnn.com/2011/HEALTH/03/10/ep.neuropathy.kids.hearing/index.html?hpt=C2) about the misdiagnosis of auditory neuropathy/auditory dyssynchrony (AN/AD). At the Iowa EHDI conference in September, 2010, Marilyn Neault, Ph.D., was our guest and gave an excellent presentation on this topic.



We are glad this issue is getting attention in the popular press because we all need to be aware of the unique challenges for kids with auditory neuropathy/auditory dyssynchrony (AN/AD) and their families. We didn't even know this condition existed until about 15 years ago. As the CNN article points out, the first challenge can be an accurate diagnosis! The diagnosis really requires an auditory brainstem response (ABR) evaluation AND otoacoustic emissions (OAEs). Because AN/AD occurs far more frequently in NICU babies than well babies, in 2007 the JCIH recommended automated ABR screening in the NICU and said OAEs in the well baby nursery are fine. There are some points in the CNN article that may be somewhat misleading for families and we want to respond to those:

First, for such a misdiagnosis to happen, the original audiologists didn't do OAEs as part of their diagnostic evaluation. We're not aware of any pediatric audiologists in Iowa doing good pediatric ABRs who would not also include OAEs in evaluation.

Second, given that the child was diagnosed with moderate loss, it's not likely amplification that was safely fit would have damaged his hearing.

Third, of course we want parents to trust their instincts, but we need to caution parents about keeping hearing aids off a child who seems to be hearing, especially in the case of high frequency cochlear hearing loss. These kids respond well to environmental sounds, but will not reach speech and oral language goals without being able to hear all of the speech signal.

Last, although some claim that hearing aids don't help people with auditory neuropathy, there is evidence that many do. We have clinical experience with such patients in Iowa and Dr. Neault discussed this in her presentation in September, too. Outcomes with cochlear implants have been

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Auditory Neuropathy/Auditory Dyssynchrony in the News

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outstanding for some children, but great caution is urged because some AN/AD can resolve spontaneously in the first 14 months of life. Other successful management strategies include sign language, cued speech and FM amplification.

So, we do want to make families (and audiologists!) more aware of the danger of misdiagnosis of AN/AD and that's why we need more people doing good pediatric ABRs. It's a complex condition with several possible sites of disorder and intervention will never be "one size fits all."

Written by Lenore Holte, Ph.D., Lead EHDI Pediatric Audiologist

Success Story: St. Luke's Regional Medical Center

During late 2009 and early 2010, discussions began among EHDI program team members regarding where to place an Automated Auditory Brainstem Response (AABR) infant hearing screening unit. The equipment was purchased through stimulus funds from the American Recovery and Reinvestment Act (ARRA). Several variables were considered when determining the placement of this screening equipment, including: (1) Hospital had to have a Neonatal Intensive Care Unit (NICU); (2) High refer rates on initial birth screen; (3) Number of births per year; and, (4) Geographic location of hospital (in proximity to an accessible AABR screening device).

In spring 2010, the program team determined that St. Luke's Regional Medical Center in Sioux City, Iowa would be the chosen site. St. Luke's in Sioux City met all of the criteria and did not have AABR equipment to screen NICU children as recommended by the Joint Committee for Infant Hearing screening. St. Luke's was also excited about the opportunity for their hospital and the families they serve. A formal agreement was initiated and in September 2010, 22 staff from both the St. Luke's well baby nursery and NICU were trained. Nick Salmon, EHDI consulting audiologist, and Kevin Stoltz, audiologist and sales representative from the medical equipment vendor, led the training sessions over two days. Topics addressed and activities included:

- Differences between the Otoacoustic Emission (OAE) screening and the AABR screening
- Orientation to the Vivosonic Aurix AABR system and its use and care

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Success Story: St. Luke's Regional Medical Center

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- New procedures, including:
 1. Screening with AABR all "refers" from their well baby nursery where they'll continue to use OAE for initial screening
 2. Screening all NICU infants and rescreen all "refers" with AABR
 3. Where to refer infants who do not pass the AABR hearing screening
- A hands-on practicum with infants from the NICU
- Offering to the larger Sioux City area AABR screening to those who would benefit



St. Luke's nurse performing screen using new ABR screening equipment.

Tammy O'Hollearn, State EHDl Coordinator, provided support to the St. Luke's staff regarding billing procedures and data entry into the IDPH EHDl system (eSP™).

It is important to note that some systemic changes began to take place following OAE training in November 2008 and an EHDl hospital site visit by Nick Salmon and Tammy O'Hollearn in June 2009, as evidenced in the refer rates table below. Placing the AABR screening unit at St. Luke's Regional Medical in 2010 further reduced the number of referrals and missed birth screens and also provided St. Luke's with the opportunity to also rescreen those babies born at their hospital who did not pass their birth screen, thus reducing the number of infants lost to follow up. In addition, the EHDl program team recognizes that Taffy Benson, Director of Maternal Health and Children's Services, Tracy Kunkel, unit secretary, and other nursing team members have been instrumental in the positive changes for the birth and outpatient hearing screening processes since last summer.

	1 st Qtr	2 nd Qtr	3 rd Qtr	4 th Qtr	Yearly Total
Year	<i>Birth Screen Refer Rates</i>				
2008	14%	26%	24%	10%	19%
2009	13%	14%	8%	7%	10%
2010	8%	4%	9%	1%	6%
2011	3%	3%*			

* Through May 2011

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Success Story: St. Luke's Regional Medical Center

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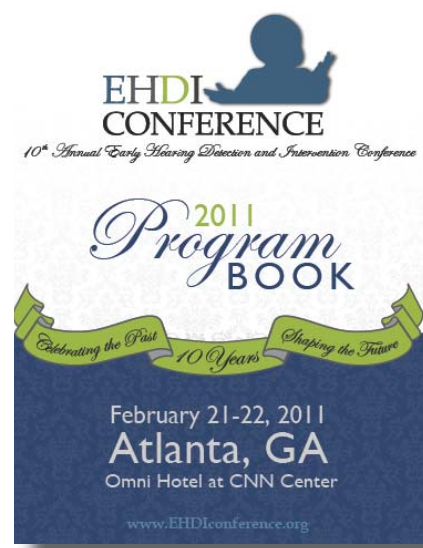
Systemic changes implemented under Taffy's leadership include a change in data entry personnel. Tracy Kunkel is assigned to complete the data entry and program support and a back-up data entry person was trained and assigned to ensure data is entered into eSP™. St. Luke's pursued having demographics data imported into eSP™ to decrease manual data entry and related errors. A new protocol was written and implemented for outpatient hearing screens. In the past the hospital gave the family information about the local Area Education Agency and told them they could take their child there for a hearing rescreen. They did not assist the families with this process and the AEAs do not have AABR screening equipment available to screen NICU children. A new process is in place now so that nursing staff assists the families in scheduling a hearing rescreen at St. Luke's or another audiologist of choice.

The entire EHDI staff wants to thank the medical team at St. Luke's Regional Medical Center for their collaboration and diligence. We look forward to working with them and appreciate their efforts to enhance the EHDI system of care.

By Nick Salmon, EHDI Audiologist; Peggy Swails, EHDI Follow up Coordinator; and Tammy O'Hollearn, State EHDI Coordinator

EHDI Conference 2011

The 10th Annual Early Hearing Detection and Intervention Conference: Celebrating the Past, Shaping the Future of EHDI Programs is in the history books, but the valuable information learned there is still being spread around Iowa! Over 800 attendees from a diverse stakeholder group came together from all over the United States and the world with a shared goal of providing better services to infants and our children who are deaf or hard of hearing and their families. Iowa was fortunate to send nine representatives from the Iowa EHDI program; Susan Hagarty, Vicki Hunting, Tammy O'Hollearn, Dr. Shannon Sullivan, Peggy Swails, Jennifer Thorud, and Dr. Debra Waldron. Thanks to the support of National Center for Hearing Assessment and Management (NCHAM), parent scholarships we were able to send two Guide By Your Side (GBYS) Parent Guides; Anne Hender-Jasper and Brandi Nielsen, both mom's of children with a hearing loss. Several in our Iowa contingent also presented sessions during the conference.



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EHDI Conference 2011

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Tammy and Jennifer presented; *An Innovative Process Improvement Tool for EHDI Programs – Hospital Site Visits and Using Program Evaluation to Improve the Iowa EHDI System*, respectively. Vicki and Dr. Waldron presented *The Building Blocks of a Medical Home for Children with a Hearing Loss*. Additionally representatives from Iowa participated in other ways by serving on panels during the conference, sitting on the conference planning committee, leading discussions and providing input to other presentations on behalf of the great work we are doing here in Iowa. Below are some comments from the Iowa participants on what they took away from this year's conference.

It was great to see the Iowa EHDI system of care well represented at this important conference! There were several sessions during the conference on the topic of EHDI and medical home, and our team presented one of the sessions. As it turned out we had a little different perspective than some of the other sessions and it was well attended. Vicki and I presented 'The Building Blocks of a Medical Home for Children with Hearing Loss' with Alan Grimes, MD, FAAP, a pediatrician in private practice in Kansas City, Missouri. Dr. Grimes serves as the Missouri EHDI Chapter Champion and participates on the AAP Task Force on EHDI. Our presentation concentrated on three important areas of a medical home within EHDI; clinical practice, state systems, and the parent/family perspective. Dr. Grimes talked about how EHDI fits into today's clinical practice: what that looks like and why it's important to families and the community. I spoke about the important work we have done in Iowa on the Title V perspective to create and sustain effective community-based systems of care. Vicki wrapped up our presentation with the perspective of raising a child with a hearing loss and what parents need and want from professionals and the community.

It is important that children and their families have a medical home and receive the care that they need from a medical team whom they trust. We have done great work in Iowa ensuring that our children are screened, identified, and receive the appropriate and timely services they need. I look forward to what the future has to hold, as we continue to improve our approach to providing these services in a high-quality and cost-effective systems-based manner.

- Debra Waldron, MD, MPH, FAAP, Vice Chair - Child Health Policy and Statewide Health Services at the University of Iowa College of Medicine, Department of Pediatrics; and the Director and Chief Medical Officer of the Child Health Specialty Clinics: Iowa's Title V Program for Children with Special Health Care Needs

I had the pleasure of attending the tenth annual Early Hearing Detection and Intervention Conference (EHDI) Feb 20th – 22nd in Atlanta, GA. There were over 800 attendees who consisted of stakeholders from all over the United States. Everyone who attended shared the same goal; to provide better service to infants and/or children who are deaf or hard of hearing, and support to those families.

I attended many valuable sessions ranging from language modality outcomes to speaker panels on views of deafness. Howard Rosenblum's (who will be taking the position of CEO this April for National Association of the Deaf (NAD)) presentation was by far my favorite. His presentation

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EHDI Conference 2011

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was titled **"It's All About Expectations!"** He shared a success story about a group of deaf and hard of hearing students that he had gone to elementary school with. His presentation included no names, but only a class picture of former class mates when they were younger. As each former student's individual picture was circled on the screen, he focused on the low expectation of what that child was given and where they were at today. Currently, all of the children shown in his class picture are successful, thriving contributors of their community. There was one young girl in the picture he discussed ...although never named ...I believed to be Marlee Matlin.

His message was simple; just because a child is deaf or hard of hearing, our community should not lower their expectations of this child, but help that child nurture their dreams and motivate their opportunities in life.

– Anne E Hender-Jasper, parent of a child with a hearing loss and Iowa GBYS Parent Guide

This year's conference was my first EHDI conference. I was very excited to be able to talk with other states and identify what they are doing for program evaluation and how we can improve or change what we are doing. I also wanted to get ideas on what other states are doing to increase their integration with other data systems.

Through the sessions as well as the responses I received after my presentation on Iowa's program evaluation efforts, I realized that Iowa is really doing a great job. I received a number of surveys used by other states that may help us in future evaluation planning related to processes at our hospitals, outpatient screening providers and audiologists, as well as infants diagnosed with hearing loss (similar to our parents survey) and infants lost to follow up or lost to documentation. Overall, I think we are doing some great work at being able to evaluate our progress throughout the year and report our findings back out to our stakeholders. We have a ways to go in some areas of our system to make improvements and efficiencies, but in general, we are doing well. Integration will be a focus in our next grant cycle. We will be making small steps to reach this goal, and it is something that will take time. Although we are not integrated with vital records, the quality assurance work we do, such as our data match between our EHDI data and with birth certificate data and follow up on missing infants, really helps us to ensure we account for all births in our state. This allows us to truly be able to see each infant's progress through the EHDI process and help identify ways we can continue to improve the system.

- Jennifer Thorud, Iowa EHDI Program Evaluator

Every year I look forward to the national EHDI conference. It is an opportunity to become re-energized and learn about new best practices within the world of EHDI! It is a great opportunity to reconnect with old friends, parents of children who are deaf or hard of hearing, advocates, national partners and my colleagues (EHDI coordinators) in other states. Reconnecting with my colleagues affords me the opportunity to learn what they are doing, which in some cases helps us avoid reinventing the wheel in our own state! It is an opportunity to learn about their successes or challenges and ask questions. At the same time, I get to share the same information about initiatives we have going on in Iowa.

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EHDI Conference 2011

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I learned many things at the national conference again this year. However, I was very interested in learning more about hospitals and audiology clinics successful in using the Vivosonic Integrity equipment to perform unsedated auditory brainstem response assessments on children who are older than one month of age. I enjoyed hearing from Dr. Albert Mehl about the medical home and EHDI and how the relationship between the two has evolved over time, but there is still much work to do. Dr. Mehl is very practical. He reminded us that one size does not fit all, but also gave some suggestions for things that may work or help bridge the gap. I liked how he suggested using "developmental emergency" in the primary care provider letter to catch their attention on children who did not pass their hearing screen(s). Other sessions I found useful information were where states spoke of strategies being used to reach families of children born outside of the hospital setting to ensure those children receive timely hearing screens, data integration, and outreach through public health nurses. Finally, one of the most important messages is that we need to celebrate our progress! Iowa has accomplished a great deal in the last five years and we have much to celebrate.

- Tammy O'Hollearn, Iowa EHDI Coordinator

It was fantastic to network with the other EHDI Chapter Champions at the conference! One session that I attended was particularly interesting for me (as a former neonatologist) as it dealt with the optimal time for follow-up hearing screening for NICU grads. Currently infants who were in the ICU for greater than five days are "high risk" and need follow up evaluation – typically at 24 months. This brought up some interesting questions worth discussing further; within this population are there infants for whom closer follow up would be prudent? Are there data that might shape current follow-up recommendations for this high risk population in the future? What additional screenings are neonatal intensive care units doing around the country?

When I returned home I discussed this topic with our neonatal high risk follow-up clinic here at the University of Iowa and discovered some ways in which follow up for our NICU graduates could be improved. Stay tuned for more information on this in a future edition of the EHDI news.

– Shannon Sullivan, MD, Iowa AAP EHDI Chapter Champion, Clinical Associate Professor of Pediatrics & Director Newborn Nursery – UI Children's Hospital

"Go beyond the language." ~ Maria Rodriguez, Colorado. Maria participated in the closing plenary session of the conference entitled, "EHDI & Family Support: Past, Present and Future." Maria is a Latina Guide By Your Side (GBYS) Parent Guide for Colorado's Hands & Voices chapter. Maria is married and her spouse is non-English speaking. They have a 6-year old daughter who has a bilateral profound hearing loss and received a cochlear implant at the age of two.

Maria's message focused on the future of EHDI. I found her message to be most intriguing. Iowa's EHDI is currently seeking a Spanish speaking parent guide for the Guide By Your Side program. It is important that we take heed to Maria's message with regard to culture and "go beyond the language."

Maria challenged conference participants to share her vision for the diversity, customizable flexibility, and expansiveness of parent support programs of the future. Understanding and appreciating intercultural differences ultimately promotes clearer communication, breaks down barriers,

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*builds trusts, strengthens relationships, opens horizons and gives tangible results when we **go beyond the language**. This means that we recognize and understand that culture expands to include religion, beliefs, values, and ethics.*

*For intercultural communication to really work, people need to wonder why they hold those ideas or beliefs. In doing so, and even to openly discuss the others, is to overcome the initial barrier for intercultural communication and **go beyond the language**. Maria provided us with a glimpse into a "perfect world" after what occurs once a baby has been newly identified with a hearing loss. It is my hope that each and every one of us will embrace Maria's vision as we continue to enhance the Iowa EHDI System of Care.*

- Peggy L. Swails, LMSW, Iowa EHDI Follow-up Coordinator

*This was my third EHDI conference and must admit my favorite so far (but I say that every year!). My take away from the plenary session by Dr. Albert Mehl, "The Medical Home and EHDI" had to do with how we as a state EHDI program approach the medical community and other stakeholders in our system of care in educating and informing them on newborn hearing screening; why it's important and what they need to know. The approach Dr. Mehl offered up was simple; it should be "just in time" learning! This kind of learning arrives "just in time," clearly states what the parent or professional needs to know or do, why the information is important, and where they can go to get more information. He likened it to Batman; every Bruce Wayne needs an Alfred. "Just in time" learning, Batman style, is served on a silver platter, arrives before Bruce even knows he's hungry, portion sizes are dainty and it comes with information about where to find more if he's still hungry!! As we work toward strengthening our EHDI system of care in Iowa we are always looking for ways to inform our stakeholders of the importance of **early detection...every infant...every time** and this presentation really caught my attention.*

- Vicki Hunting, Iowa EHDI Program

This past February I was privileged to attend the 10th annual National EHDI conference in Atlanta, Georgia. In addition to several Iowa colleagues, over 800 attendees from all areas of the country were present with a wide variety of professional and personal backgrounds being represented.

The main sessions of the conference really demonstrated the extensive advancement and growth in the EHDI program. I found it interesting to see the difference in how the EHDI program used to be and how it has evolved into the EHDI program we know today. The presenters all expressed the need for continued growth and intense focus on the importance of high quality family support, both formal and informal.

The conference was a great experience for me, as the parent of a deaf child and as a parent guide. It was wonderful to gain valuable insight from others who share similar experiences and challenges while raising a child with hearing loss. Everyone was so willing to contribute their thoughts and ideas that I felt an overwhelming sense of support and encouragement. I look forward to sharing my positive experience with the families I currently support.

- Brandi Nielsen, parent of a child with a hearing loss and Iowa GBYS Parent Guide

EHDI Conference 2011

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After a few days in Atlanta Georgia, I came back to Iowa excited about the possibilities for growth and improvement within our EHDI System of Care. Specifically, I was motivated to move forward in our efforts to help Iowa families establish and maintain a medical home for their deaf or hard of hearing child.

Dr. Albert Mehl shared his thoughts and expertise on medical homes in a plenary session. I was particularly drawn to two analogies he used to illustrate the important role of the primary care physician and the importance of "just in time" learning. The role of the primary care physician he likened to the conductor of an orchestra. Although many conductors are talented musicians themselves, and may even play several different instruments quite well, their job is not to learn, practice, perfect, and play every instrument and part within the symphony. Their job is to coordinate, orchestrate, and inspire those talented artists that make up the entire medical home. They do this by being comfortable with their own ignorance, committed to education, cooperative with non-physician providers, connected with the family, and compensated for the extra time and effort that goes into establishing and sustaining the medical home.

Dr. Mehl's speech also explained what is meant by "just in time" learning. He used another analogy to illustrate this concept. As he spoke, a giant Batman symbol appeared on his presentation screen and reminded us all of Alfred, butler to the billionaire Bruce Wayne. Alfred knew how to provide "just in time" learning for Mr. Wayne as demonstrated by the food service he provided. It was served on a silver platter (attractive, accessible); given before Mr. Wayne knew he was hungry (not when desperately needed); made up of a dainty portion size (not over-whelming amounts); with more food available in the kitchen (providing continued support).

Both the conductor and Alfred the butler have a great deal to teach us about service to our families. Whether we are trying to establish medical homes, or simply providing support, these fundamental approaches will lead us to better outcomes.

– Susan Hagarty, parent of a child with a hearing loss and Iowa GBYS Program Coordinator

*Never doubt that a small group of thoughtful, committed citizens could change the world. Indeed, it's the only thing that ever has."
– Margaret Mead*

Feel free to peruse the conference presentations on the National Center for Hearing Assessment and Management (NCHAM) website at www.infanthearing.org/meeting/ehdi2011/index.html.

Deaf and Hard of Hearing Children's Educational Bill of Rights Update

Iowa Hands & Voices, the Iowa Association of the Deaf, and Deaf Services Commission of Iowa have been working together to see passage of a Deaf and Hard of Hearing Children's Educational Bill of Rights. It was introduced by Senator Sodders. Then it was referred to Education Committee. The committee's report recommended passage. As the legislature was approaching the end of the session, the bill died, and will not be moving forward.

If you have questions, please contact Suzy Mannella with the Office of Deaf Services at 515-598-7327 or SuzyMannella@iowa.gov.

Tired of Entering Demographics and Hearing Results Manually

...Consider Importing

Do you want to save time entering demographics and hearing screen results into eSP™? Consider joining your peers across Iowa and import demographics and hearing screening results into eSP™. Importing the demographic data not only decreases the amount of staff time for manual entry, but also decreases duplication (manual entry into multiple data systems), avoids missing children, and decreases the potential for errors in spelling or results entry.

eSP™ interfaces with hospital data registries (e.g., admitting or electronic health records) to import data from the hospital's database into eSP™. This involves the creation of an ASCII file that contains patient information including demographics, contact information, race/ethnicity and risk factors. One field that will still need to be entered at this time is the PCP/medical home.

No software is needed to enable you to do the import. The EHDI program will provide instructions and the data dictionary needed to create the file so the information can be passed along to hospital information technology (IT) personnel. Once the file is created, the EHDI data base vendor, OZ Systems, will test the file to ensure it works correctly. Once the file has been tested, EHDI staff in collaboration with OZ will schedule a Webex to walk you through the steps to set up the import.

If you are interested in learning more about importing, please contact Tammy O'Hollearn at tammy.ohollearn@idph.iowa.gov or by phone at (800) 383-3826. If you set up the system to import demographics, you can also set it up to import newborn hearing screening results too. Join your peers and save time by setting up an import file today!

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

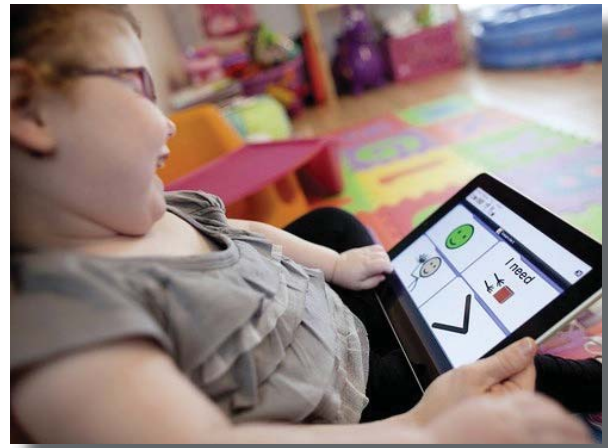
Your single point of contact to assist families in connecting with Early ACCESS and community-based services that address specialized child and family needs

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

www.EarlyACCESSIowa.org

Mississippi Bend AEA Students Become Familiar with New Technology

For the past several months, hearing impaired students within the Mississippi Bend AEA districts have been given the unique opportunity to become familiar with new technology, including assistive devices. Audiologists from the MBAEA acquired funding through state Teacher Quality Monies and the Riverboat Development Authority (RDA) Grant which enabled them to purchase the equipment that now comprises the Hearing Department Loaner Library. At this time, the loaner library consists of: iTouches, iPads, Phonak MLXi receivers, Inspiro transmitters, Freedom Microlinks, MyLink receivers, iComs and TVLinks.



Children with hearing loss have the unique challenges of having limited access to sound in everyday environments. They often have speech and language delays as a result of their hearing loss. Given these limitations, children with hearing loss fall behind their normal-hearing peers academically and socially, which can affect their ability to achieve success and become active members of our community.

Hearing impaired students typically have language delays which affect their ability to read and write. They have gaps in vocabulary development. They often don't understand words with multiple meanings, abstract, and functional words. Children with severe to profound hearing loss usually achieve skills no higher than the third- or fourth-grade level, unless appropriate educational intervention occurs early.

Socially, conversations with friends and family, meetings, phone calls and watching TV can be particularly challenging. In many cases, kids with hearing loss will withdraw and become socially isolated. Their quality of life diminishes noticeably. By providing them with ways to access these things that normal hearing students use everyday, we can improve their quality of life.

Our goal is to provide new technology and assistive devices to hearing impaired students and their families. As part of the 21st Century, our hearing impaired students need to interface with a diverse range of communication systems: iTouches, iPads, cell phones, TVs, MP3 players, computers and other audio sources, through the use of assistive devices. These devices will give students access to their teacher's voice no matter where he/she is in the classroom with the FM unit. They will be able to hear the computer in the classroom, and the iCom will provide them

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Mississippi Bend AEA Students Become Familiar with New Technology

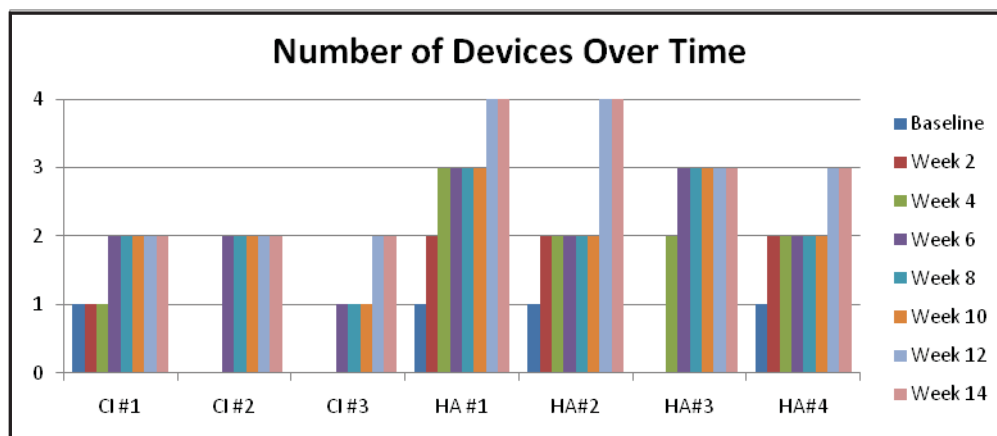
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access to Bluetooth devices, such as the iTouch, iPad, cell phones, FM systems, TVs and MP3 players. Our objective is for hearing impaired students to become more independent and more familiar with the technology available to them. Through the use of iTouch/ iPad, they are able to access educational applications for math, science and reading, as well as reference applications and games.

Students, teachers and families were educated about the devices, which were provided for use within the home and at school. The audiologists devoted time for demonstration and completion of instructional activities with students. Usage was monitored biweekly over the course of several months to address needs and/or questions that arose.

Initially, seven students participated in the program. However, after a protocol has been established, these devices can be used by any of the hearing impaired students within AEA 9 through a loaner library. We hope to build a large device inventory that will allow us to provide services to a greater number of hearing impaired children and their families. The items will be available to hearing impaired students for check out for a month or more at a time.

To monitor the growth of the student's ability to access sound and information independently, we charted the number of pieces of equipment used by each child. We also used feedback from students, parents and teachers to improve and adjust our services for next year.



Resources for educational applications to be used on the iTouch or iPad:

www.babieswithipads.blogspot.com

www.momswithapps.com

www.connsensebulletin.com/2010/05/apps-for-education

www.bestkidsapps.com

www.cooliphoneipadapps.com

14 www.funeducationalapps.com

Nursery Rhymes and Deaf Infants

Before I became deaf at five years old, I had the advantage of being exposed to nursery rhymes, songs, and lullabies in my infant/ toddler years. During those years, my parents recalled there were times I cried often and they had to give me a lot of attention, often using sounds to soothe me. My wife, who is also deaf, and I raised five hearing children and have often used calming methods of talking, singing in hymns, and using lullaby cassettes and sing-a-long Disney videos. It didn't take much for us to see that the use of sound played a big role in consoling our children.

While we did not have a deaf baby and do not recall any of our close friends having a deaf baby, the thought of what would we do to relax and help rock a deaf baby to sleep or console their crying never occurred to us. We never encountered that experience or thought about it until we met an old deaf friend, Mario Pizzacalla, at the Bilingual Deaf Coalition conference in Milwaukee, Wisconsin in 2008. Hailing from Ontario, Canada, it had been about ten years since I last saw Mario and I recall that he worked as printer at a Ford factory in Toronto and spent several evenings a week teaching sign language in his hometown near Niagara Falls, New York. Mario, full of enthusiasm and optimism, shared with us about his new job which he accepted after leaving the Ford factory. Mario is a short guy of Italian descent who often listens to people's stories and problems with heartfelt support. He cares for others and wants the best for everyone he meets. At the conference, Mario told us he had the best job in his life. It was funded by a grant that he hinted would probably only last a year. My wife and I had to share! We found a restaurant outside near a canal to listen to



Mario (communicating in American Sign Language) share his new passion. The following is a narration of Mario's story:

"I am now a guide to parents with deaf babies. I never thought this would work but after visiting parent after parent, I got more excited and certain this is the right thing to do. Our program obtained a 2-year grant but we hope we can continue this with some funds from another source. There is no question people do not realize how much of an impact this program has. I never thought about what I would do if one of my two children was born deaf. I assumed that my wife and I being deaf would not present a problem raising him/her; however, when we hear how parents use sounds to calm their baby, I began to wonder what I would do to calm a deaf infant. Have you thought about this? (When he asked this, I agreed that I was clueless!)"

Let me tell you what I usually do. A hearing advocate--serving as an interpreter and coworker--and I visit parents of deaf infants weekly at their homes and teach them sign language, model how they should interact with their deaf baby, and encourage them to adapt to the deaf baby's world rather than to focus on trying to "fix" the baby's deafness. It is our program's policy for me, as a deaf person, to initiate conversations with the parents, not the hearing advocate. Naturally, most hearing parents are afraid to talk with deaf adults

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Nursery Rhymes and Deaf Infants

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out of awkwardness and uncertainty. I explain that their baby is deaf and they need to be prepared realistically. The hearing advocate helps to interpret the conversations, with all questions and comments being directed to me. This helps the parents and me to establish a relationship, exposing them to the use of sign language in the process as a means of fostering communication with their deaf child. (I thought that was awesome and challenging!)

But this is just one part of my work. Something else almost always happens. During my visits to their homes, their babies will cry at one time or another. The mother, and sometimes the father, would try to calm their baby after feeding or changing diapers. They try not to appear frustrated as at times the baby shoves, cries and gets restless. With their permission, I ask them if I can show them something.

They always let me help. They would hand over their infant to me and I would hold the baby for a short while. The crying and fussing usually stops but not for long. Next I would lay the baby down, facing up to see me. While the infant would look at me, I would sign short nursery rhymes. (He showed us a sample of simple sentence structures with facial expressions and body rhythms to indicate what he does.) The baby keeps looking at me, responding with smiles and laughter, and moving their arms. Almost always the crying would cease during my visit. The parents were often awed, sometimes with tears, and sometimes express frustration why they could not do this. I encourage them and tell them we will work through it.

You know why this works? Simply this: Deaf babies do not hear¹. They see. They need the communication feedback with their eyes. Sign language is a language ready for them and it stimulates their learning. Oftentimes the parents seek help for their deaf babies in the wrong places and in the wrong ways. Some parents try to tickle their babies but it works only for seconds. By alternating signing and touching, this works wonders. The parents keep asking me to come again. They get motivated in learning American Sign Language. We don't know any other programs doing this but some people hours away want us to come. We can only help those in our region and hope to train others to support parents of deaf babies in other provinces and the U.S."

What Mario shared was something we will never forget. Unfortunately, his work with the program has progressed slowly because of a lack of additional funding. What he shared does bring optimism because there are ways to connect and comfort deaf infants when sound is not their option. In the next EHDI newsletter, look for another article summarizing the program and including briefings from articles written by those involved in this program.

By Bob Vizzini, EHDI Advisory Committee Member, Advocate

¹While many of these babies may hear to some degree, the point is they cannot hear adequately the soothing sounds nor identify the sound of their mother calling their name or their favorite lullaby. They are not audio stimulated as they are readily visual stimulated.

Mario Pizzacalla's program created a book and DVD, "The ASL Parent-Child Mother Goose Program: A Video American Sign Language Rhymes, Rhythms and Stories for Parents and their Children" (currently taken on by the Ontario Cultural Society of the Deaf). You can view Mario explaining the 2007 program promotional video:

www.youtube.com/watch?v=bXurwa9scX0.

Through Your Child's Eyes: American Sign Language Video

Through Your Child's Eyes: American Sign Language (www.throughyourchildseyes.com) is a thirteen minute video presented in American Sign Language (ASL), English and Spanish. The video is designed for parents of newly diagnosed children who are deaf or hard of hearing and secondly for professionals who work with deaf and hard of hearing children.



The video brings to light the benefits of maximizing a deaf or hard of hearing child's instant strength: his/her eyes. It provides parents with a framework for understanding the value of, and need for, American Sign Language within the scope of early language acquisition for all babies, but particularly those who are deaf or hard of hearing. You will also hear from parents on their experiences.

The video was produced by DJ Kurs in collaboration with California State University, Northridge and California Department of Education.

Infant Hearing Screening

A Sound Beginning for Your New Baby



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

Summer Camps

DSCI Junior Commission Program Leadership Camp, Dolliver State Park, Lehigh July 18 - 23, 2011:

Application forms are available on website at www.deafservices.iowa.gov/youth/junior-camp.html.
Deadline for registration and submission of the \$50 fee is by Tuesday, May 31 and registrations will be considered in order received.



This camp offers a unique opportunity for leadership development among deaf, hard of hearing, and hearing teens. An intense, six-day curriculum focuses on eight core leadership power tools: communication, conflict resolution, decision making, goal setting, group dynamics, leadership techniques, project management, and self-awareness. There is also adventure learning, mentoring, games, skits, and just plain fun. For many teens, this may be the first time they have interacted with other Deaf and hard of hearing teens and adults. Participants will meet peers who have similar and different experiences. Most importantly, this program opens communication among deaf, hard of hearing, and hearing teens. The camp participants are any student who is enrolled in an Iowa school in grades 7th through 12th. Students may be deaf, hard of hearing, deaf-blind, late deafened or hearing. Former participants include those interested in Deaf Culture, hearing loss, pursuing a career in the field of interpreting or deaf education, a KODA/CODA (Kid/Child of Deaf Adults), have a cochlear implant, speak American Sign Language, use Signed Exact English, use real-time captioning, use assistive listening equipment, etc.

For more information about this camp, please contact Suzy Mannella with the Office of Deaf Services at Suzy.Mannella@iowa.gov or 515-598-7327 (VP/voice).

Iowa School for the Deaf Summer Camp Council Bluffs

July 17 - 22, 2011:

Registration is now online at www.iowaschoolforthe deaf.org. Contact ISD for paper forms. May 20th is the last day to register and submit the \$25 fee.

This camp is for school-age children in Iowa who are deaf, hard-of-hearing and hearing-impaired, use spoken or sign language, have cochlear implants, hearing aids or no assistive devices, and who will enter pre-school through 12th grades in the fall of 2011. For students staying in the

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Summer Camps *continued from page 18*

dorms, a \$25 activity fee will be due at camp check-in (one activity fee per camper). For more information, contact:

John Cool (dorms, transportation, food, health center, recreation): jcool@iowaschoolforthe deaf.org or 712-366-3241

Rebecca Gaw (9th - 12th grade program) rgaw@iowaschoolforthe deaf.org or 712-366-3237

Shari Slater (preschool - 8th grade program) sslater@iowaschoolforthe deaf.org or 712-366-3227

Sertoma Camp

Brainerd, Minnesota

Session 1: 1st - 7th grade from July 10 - 15

Session 2: 8th - 10th grade from July 17 - 22

Registration is due by June 1. You can register at www.campsertoma.com.

"Campers are from both rural and metro areas of the Great Plains regions (Minnesota, North Dakota, South Dakota, Iowa, and Nebraska). This is a once-a-year opportunity for many of the kids to be with other kids with similar experiences, and feel no judgment. When a child is in an environment with no communication barriers, they build new friendships, and have great role models, their self-esteem sky-rockets, naturally."

For more information about camp, please call 218-828-2344 (voice), 866-948-9063 (VP).

Other Summer Camps for Deaf and Hard of Hearing Teens:

www.gallaudet.edu/clerc_center/information_and_resources/info_to_go/resources/summer_camps_for_deaf_and_hard_of_hearing_children.html.



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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.