Present: Kathryn Baumann-Reese, Marcy Bieseigel-Clausen, Melissa Carlson, John Cool, Marsha Gunderson, Diana Hanson, Roger Hess, Jeffrey Hoffman, Lucinda Hollingshead, Lenore Holte, Barb Khal, Dennis Konkel, Joan Marttila, Sally Nadolsky, Steve Sword, Bob Vizzini and Amy Wallin

Staff: Tammy O’Hollearn, Erin Kongshaug and Emily Andrews

Introductions and Announcements (Tammy O’Hollearn)

New EHDI Advisory Committee Members
Tammy welcomed five new members to the EHDI Advisory Committee:
1) Melissa Carlson from Child Health Specialty Clinics who is the part time EHDI Family Support Coordinator and part time CHSC service coordinator.
2) Dr. Jeffrey Hoffman who will represent the Iowa Academy of Family Physicians.
3) Lucinda Hollingshead is a nurse at Mary Greeley Hospital and hard-of-hearing adult.
4) Bob Vizzini who is an ASL instructor at Kirkwood Community College and advocate.
5) John Cool will replace Jeanne Prickett as the representative for Iowa School for the Deaf. John is the Director of Student Life at the Iowa School for the Deaf.

Iowa EHDI Best Practices Manual
The Iowa EHDI Best Practices Manual is now available on the EHDI Web site, professionals’ page, www.idph.state.ia.us/iaehdi. The purpose of the manual is to advance the development of a comprehensive statewide early hearing detection and intervention (EHDI) system in Iowa. The goal is to assist hospitals, birth centers, Area Education Agencies (AEAs), health care providers and private practice audiologists in developing programs and written protocols for newborn hearing screening, follow up and intervention. The manual is based upon best practices within early hearing detection and intervention programs and Iowa EHDI law and rules. The manual will be distributed to all hospitals and Area Education Agencies at the beginning of February.

EHDI Family Resource Guide
The English EHDI Family Resource Guide has been revised and is also available on the EHDI Web site under the parents and professionals’ page. The Spanish version will be available in February. A small number of guides have been printed and will be distributed
to audiologists at the AEAs, as well as private practice audiologists that work with children.

**Legislative Updates**
Tammy reported that the proposed changes in the Newborn Hearing Screening law will move forward this legislative session through the IDPH Omnibus Bill. If approved by the legislature, then the changes to administrative rules will be submitted. She thanked EHDI Advisory Committee members for reviewing the proposed changes, making comments and asking questions last fall. Tammy reported that no committee members expressed concerns either time they were distributed to committee members. She thanked those members who wrote an e-mail in support of the proposed changes. A copy of the proposed changes was also shared with the staff to the Audiology Board.

Kathryn Baumann-Reese asked if the Hearing Aids and Audiological Services funding would be affected by the proposed state budget cuts. Tammy said that the funding appears to be safe through June 30, 2009, however she cautioned that could change during session. Tammy also said that the funding would most likely be cut if the Department (IDPH) is asked to cut their budget more in the coming months.

**Pediatric Audiological Healthcare Directory**
Provider templates are being finalized and being e-mailed to providers to ensure the information reported in the Directory is still current. The program hopes to have the directory available online by Spring.

**Iowa Symposium on Hearing Loss (Lenore Holte)**
Lenore provided members with a summary of the symposium’s existence. The majority of the costs are paid for through a professional development grant through the Centers for Disease Control.

The symposium has been around for approximately 10 years. It was originally held in a location in Iowa City and later moved to the Scheman Center in Ames to be more centrally located. The symposium is held every other year. The symposium is a high quality program with continuing education credits being offered at a low price for professionals. In addition, the committee is working to increase parent and nurses attendance at the symposium. Scholarships are offered for parents who cannot afford to attend and for nurses who work directly with the EHDI program. Lucinda recommended that there be a specific track for nurses with topics pertaining to their work in the hospitals or increase the amount of time in the screening lab. Lucinda also commented that she appreciated the time in the fall with Nick and Emily because she was able to learn from them, in addition to other facilities.

At the symposium in September, there were 110 registrants, 9 exhibitors and 11 parents who attended the conference on Friday and Saturday. This year the symposium started at 1:00 p.m. on Friday and continued until Saturday at 3:30 p.m. The symposium was well received. Comments about the symposium and speakers were sent out prior to the ICN meeting for the committee members to review.
Lenore reported that plans are underway for the 2010 Symposium. She reviewed proposed dates, possible locations, and asked for suggestions regarding speakers. There was a suggestion by the conference planner, Sara Patkin to move the Symposium to Ankeny. The location is still central and would help with costs and logistics for speakers traveling from out of state. The grant is due March 2nd to CDC.

The following recommendations or suggestions were made by advisory committee members. Proposed speakers included: 1) David Sindry (auditory-verbal therapist) to speak about language stimulation. A number of members said he is fun, the sessions are engaging and he has great suggestions based on research and experience. 2) Amy McKonkey (speech-language pathologist) CI Teams. The recommendation is for her to speak about early intervention and communication development. Amy is also fun, has many great suggestions for language and speech development and is a great advocate for parents. 3) Karen Kirk – part of the CI team at Indiana University. Lenore reported that she will be joining the U of IA team. She may speak about speech perception or communication. If anyone else has recommendations for speakers, please send those suggestions to Lenore Holte.

Guide By Your Side (Erin Kongshaug and Melissa Carlson)
Erin introduced Melissa Carlson as the part-time EHDI Family Support Coordinator. Melissa also works part-time as the EA Coordinator for Child Health Specialty Clinics.

Melissa stated that she has worked as a speech language pathologist and Montessori preschool teacher. She shared that her daughter was identified with a hearing loss at a young age. Initially she was not connected with Early ACCESS or other families with Deaf or hard-of-hearing children. In 2007 Melissa heard about the Guide By Your Side program that EHDI program personnel were rolling out. Melissa thought her experience as a parent and teacher would be a good connection with the program.

Melissa talked about the GBYS program. She explained that the program has parent guides and Deaf or hard-of-hearing adult guides. The guides are typically parents of children who are Deaf or hard-of-hearing or are adults who are Deaf or hard-of-hearing. Melissa outlined the following goals for the guides:

1) listen, listen, listen
2) provide hope and share their family’s journey
3) provide information about resources available to the family or their children in an unbiased way

Erin shared that she and Melissa are in the process of meeting with all AEA audiologists and EA regional liaisons. The purpose of the meeting is to increase referrals to the GBYS program by:

- sharing information about the Guide By Your Side program and how the guides can support families
- introducing AEA staff members to the parent guides in their area so they feel more comfortable making referrals
- learning what can be done to increase awareness about the program.
As of this meeting, the program has less than ten referrals to the program.

Melissa and Erin shared that the guides will receive quarterly training in areas such as transition from Part C to Part B, new technologies, providing unbiased support and other important topics. Although the guides will receive this training, their role is not to be the “expert”, but rather a support who will assist with referrals. Rev. Konkel reinforced the need for the guides to be unbiased. He commented that many providers have biases that are sometimes very obvious and having a neural party that families can turn to will be helpful.

Thus far Melissa and Erin have received the following suggestions related to the program and increasing referrals:
1) link to EA Web site
2) inform Itinerant teachers about the program
3) disseminate a brochure

Erin shared that they are also trying to learn about any existing family support groups for Deaf or hard-of-hearing children. Melissa is coordinating a meeting of all these groups at the end of March. The goal is to bring all support programs together to learn about what they each offer and how they can work together to connect families to family support across the state.

**Hearing Aid and Audiological Services Funding (Tammy)**
Tammy reported that she continues to enroll children in the hearing aids and audiological services funding program. She reported there are some families from last year who were not able to receive service prior to June 30th who have since been helped in 2008-09. In addition, there are families whose children received hearing aids last year, but who are in need of additional items such as ear molds or batteries this year. There are approximately 158 children enrolled in the program to date. The program has paid approximately $75,000 thus far for hearing aids and audiological services costs. There are many claims that have not yet been turned in. Tammy encouraged providers to get those claims turned in quickly. It helps the program know how many more families can be enrolled.

Tammy reported that the number of providers participating in this program has increased slightly in the last couple of months. All new providers have been added to the EHDI newsletter distribution list to keep them informed about the program and other important hearing screening and diagnostic assessment information.

**Medicaid Updates (Sally Nadolsky and Steve Sword)**
Sally reported that Cathy Coppes continues to work with Steve Sword’s group to revise the rules to eliminate the use of duplicative reports for audiology billing. Medicaid is also looking at changing their position on payment of binaural implants based on new research.
**Border Babies (Roger Hess)**

Roger reported that it was brought to his attention last fall that the AEA’s were inconsistent in their policies as far as providing follow up hearing screens for children the who live on the border of Iowa. For example, there are families who live along the Iowa borders who may have a child born in Iowa, but whom actually reside in a bordering state. Roger asked Tammy to provide some data about those children born in Iowa who may have received a follow up screen at an AEA versus their home state. Roger presented the data to the Special Education Directors at their last meeting.

All Directors agreed that they need to come up with a policy that is consistent across the state from AEA to AEA. Most AEAs refer children back to their home state for follow up, however, children in the Northwest AEA region and a few in the Loess Hills area as well as a handful in a couple more AEAs have been able to receive a free hearing screen following discharge from an Iowa birthing facility if they failed their initial hospital screen.

Roger has been asked by the other Directors to meet with Tammy O’Hollelearn and Marsha Gunderson to develop policy related to “border babies.” Tammy reported to the committee members that she has worked very closely with Nebraska, Minnesota, Wisconsin, Missouri, and South Dakota over the last year to ensure children born along the border are referred back to their home state when further follow up is needed.

**AEA Audiology Summer Services**

Roger shared with the committee that he has also had some recent discussions about summer services within the AEAs, the need for consistency, planning and then communication of that plan to various providers in their local communities. Often service decreases in the summer months due to staff vacations and work contracts. Roger will continue to work with the Special Education Directors to resolve the issues and increase consistency and planning to ensure that families have a place to go in the summer months to ensure timely follow up.

**Audiological Technical Assistance (Lenore Holte, Emily Andrews)**

Nick Salmon sent a report for Tammy to share with the committee in his absence. Nick reported providing technical assistance, training, and support to Sioux City and Broadlawns. Sioux City has decreased their refer rate from 25% in the last couple of years to 10% in the most recent month reviewed following additional training and technical assistance from Nick and Tammy.

In addition, Nick has spent time educating the hospitals with NICUs in his area about recommended best practices from the Joint Committee on Infant Hearing regarding AABR screening for children in the NICU and risk factor reporting for children at increased risk of late onset or progressive hearing loss. Nick reports that a couple of hospitals are exploring the possible purchase of AABR equipment and/or being able to provide outpatient AABR screens. Lucinda shared that she totally supports the recommendation and they have the equipment, but the location for the outpatient screen
is a challenge. Nick is working with management staff at Mary Greeley to explore this issue.

Emily reported that she has also been working with hospitals with NICUs in her area on the recommendation for AABR screens. She said that the equipment is available in one hospital, but the challenge for them is location, as well. They cannot bring the child back to the floor. Great River Medical Center has been working hard to purchase the AABR equipment and intends to provide this service in the near future.

Lenore reports providing education to physicians, nurses, and audiologists concerning risk factors, AABR screening, and 2007 JCIH recommendations. Lenore reported that she and Erin are scheduled to speak at the Perinatal Conference in April about children with risk factors for late onset or progressive hearing loss. Tammy reported that Erin wrote an article that was submitted to the Iowa Academy of Family Physicians about newborn hearing screening and follow up. An article will also be submitted to the Perinatal Newsletter. Kathryn suggested that an article be written and submitted to the Iowa Association of Deaf about newborn hearing screening, follow up and family support. Tammy will also make contact with the nursing board to explore an article for their newsletter, as well.

Risk Factor Reporting/Follow Up (Tammy, Lenore, Erin)
Tammy reported that the EHDI program has worked very hard over the last several months to catch up on sending out risk factor letters to parents and PCP’s of children marked as having a risk factor for late onset or progressive hearing loss.

Lenore provided a summary of the process. She spoke about some of the challenges and feedback that she has received in addition to Tammy and Erin. The letter has been slightly revised and originally reviewed by parents of children with hearing loss. Tammy reported that all physicians serving children received a letter from the EHDI program about the purpose of the letters and recommended follow up this summer.

Iowa EHDI…A Work in Progress (Tammy and Erin)
Tammy and Erin summarized accomplishments of the EHDI program over the last two years and reviewed goals for the future. The Power Pointe presentation is attached to the minutes.

Next Advisory Committee Meeting
The next EHDI Advisory Committee meeting will be held on Thursday, April 2, 2009 at the Iowa Workforce Building in Des Moines from 10-3 p.m. More details regarding the location will be e-mailed to all committee members at a later date. Agenda items will include: data (screening, follow up, children diagnosed with hearing loss), legislative updates, hearing aid funding totals and an eSP Demonstration. Tammy asked members to forward any other agenda items they would like included at the April meeting.