Early Hearing Detection and Intervention Meeting Minutes
April 2, 2009

Present: Roger Hess, Stuart Trembath, Rev. Dennis Konkel, Amy Wallin, Marcy Clausen, Joan Marttila, Kathryn Baumann-Reese, John Cool, Marsha Gunderson, Diana Hanson, Lucinda Hollingshead, Bob Vizzini, Melissa Carlson, Sally Nadolsky, Debra Waldron

Staff: Tammy O’Hollearn, Erin Kongshaug and Nick Salmon

Announcements (Tammy O’Hollearn)

EHDI committee member notebooks
Tammy handed out EHDI advisory committee notebooks to all members who were present. The notebooks include a committee list and contact information, law and rules, agendas, meeting minutes, various protocols, a place for quarterly newsletters, and copies of the EHDI screening brochures.

Spanish Family Resource Guide
Tammy let advisory committee members know the Spanish family resource guide had been updated and is available on the EHDI Web site at http://www.idph.state.ia.us/iaehdi/default.asp, click on parents or professionals. There will only be five copies printed at this time. Tammy let members know that the persons who reviewed the resource guide suggested that we pair the information down for the Hispanic community the next time we look to revise the document. They felt like it was too much information.

Amish Screenings
Tammy reported that she and Erin went to meet with the Amish elders in Drakesville and Kalona to explore setting up newborn hearing screening programs in their communities. Tammy invited AEA audiologists from those regions to attend as they would be the ones administering the screens and have the expertise regarding audiology. Programs were established in both communities. In Drakesville, an elder has opened his home to serve as the location for the monthly screenings. In Kalona, the screenings are being held at the Community Clothing Center every other month. Erin wrote a brief article for the Amish newsletter (Grapevine) which includes the locations and dates that the screening will be available in those communities. The EHDI program will also work to establish screening programs in other Amish communities as they learn of other communities. Tammy said she believes that the number of refusals will decrease in those communities as well as the number of children “lost to follow up.”

Hearing Aids and Audiological Services Funding (Tammy O’Hollearn)

Tammy reported that all funding was put on hold the middle of February for the program because estimated costs for the children enrolled would expend the funding total. Tammy is exploring if the funding that was not used last year (because the program was only in place for 5 months) can be used this year. Tammy explained that she has been maintaining a waiting list of children. As claims are paid,
if there is extra money, children will be enrolled in the order in which she received the applications. If she is able to utilize funding from last year, she will enroll every child on the wait list which is approximately 30 at this time.

Tammy reported that she developed an issue brief summarizing the data available to date on this program. It is available on the EHDI Web site at http://www.idph.state.ia.us/iaehdi/default.asp, click on parents or professionals. The issue brief is at the top of the page under the section on hearing aids and audiological services. The issue brief contains sited research on the importance of early intervention, data on claims paid, ages of children needing services, number of families who had medical insurance that did not cover hearing aids and audiological services, as well as the names of those insurance companies. The issue brief will be updated over the summer and will include a year and a half of data.

**Legislative Update** (Tammy O’Hollelearn)

Tammy reported that the proposed changes to the EHDI law, that were sent out last fall to all EHDI Advisory Committee Members, were included in the Iowa Department of Public Health (IDPH) Omnibus Bill. Tammy reported that there were very few questions at the legislature subcommittee meetings regarding the EHDI portion of IDPH Omnibus Bill. The bill passed both chambers and was awaiting the Governor’s signature.

Tammy provided an update on the legislation that was put forth by Rep. Janet Petersen to require insurance companies to cover hearing aids and audiological services for children. The bill did not make it out of committee. There were many insurance lobbyists who showed up for the subcommittee meeting who were opposed to mandating insurance coverage to pay for anything. Tammy shared that the insurance companies feel that the coverage is there if the employers choose to include that as part of their plan package. Tammy provided all members (lobbyists and legislators) who attended the subcommittee meeting with a copy of the issue brief. She felt it was positive that she had preliminary data about who is being served, the number of families that have medical insurance that does not cover hearing aids and audiological services and who they are, as well as research about the importance of early intervention. In addition, she also shared that there was a wait list already because the estimates for those children enrolled will expend the remaining money.

Tammy shared that she will need to write rules this year if the funding is renewed. She reported that there is still a line item in the IDPH appropriations for hearing aids and audiological services for children. She said it had been reduced from $238,500 to $190,000. Some discussion ensued about the rules and other items that should be included in the issue brief. Stu asked if anyone and everyone should be enrolled in the program since the funds are being decreased. Stu inquired if the committee thought it would be beneficial to assemble a work group over the summer who would then invite insurance companies, hearing aid dealers, parents and audiologists to participate and explore hearing aid and audiological services coverage to see if some agreement could be reached. The committee
recommended that Stu make that suggestion to the ISHA lobbyist who has been in contact with Rep. Petersen in the past. It was noted by Stu and Kathryn that the EHDI bill passed at the national level and they were able to show the costs savings. Kathryn asked if the issue brief includes costs savings. Tammy reported that it did not, but they may be able to include it when they update it over the summer.

**HRSA Funding (Erin Kongshaug)**

Erin shared with the group that the Health resource Services Administration, EHDI will be receiving a large sum of money through the stimulus bill to be used to decrease the number of children “lost to follow-up/lost to documentation.” Erin talked about some of the challenges we have had in getting parents back in a timely fashion. Lucinda expressed concern about calls to the family at 2 weeks. She thinks it may be too soon. She also was concerned due to HIPAA.

The HRSA Project Director, Irene Forsman, said at the EHDI conference that she intends to pass along the funding to states that are already funded, but the caveat is to be creative and come up with ways to make an impact quickly (be able to show progress); not do more of the same. Erin opened it up to the group to make suggestions regarding things that could make a quick, but definite impact:

- Marsha talked about the Nebraska parent conference and possibly doing something similar in Iowa (see Sharing in the minutes below for more information)
- Kathryn suggested dedicated personnel for the children who appear to be “lost” or need to get back in for follow-up
- Stu suggested purchasing equipment that could travel to areas of the state in need of diagnostic equipment or ABR screening
- Explore options for families having transportation difficulties which keep them from appointments

**Hospital Site Visits (Erin Kongshaug)**

Erin explained that every birthing hospital will receive a site visit regardless of their performance. In the future, the EHDI team will also visit the Area Education Agencies and other private providers who serve a large number of children. Erin explained there were three hospitals, one from each level that volunteered to serve as pilot sites for visits. Erin explained that the team consists of a state EHDI staff member, audiology technical assistant and parent of a child who is deaf or hard-of-hearing. The goals for the site visits include:

- Gain a better understanding of how well-baby and NICU EHDI programs are structured and operate
- Identify strengths and needs of each birthing facility’s EHDI program
- Share best practices with each facility
- Develop a clearer picture of hospital and technical assistance needs
In addition, the EHDI program thinks the hospital staff will benefit. Hospitals will learn ways to build on the strengths of their programs and improve identified areas of concern. Best practices will be highlighted in the quarterly EHDI newsletter and shared with other hospitals who may be struggling in an area where they are successful. In addition, hospitals will learn about resources that may assist them in implementation and hear from a parent whose life has been impacted by the work they do.

Erin talked about the rubric that the EHDI team developed based on the Iowa Best Practices Manual which includes compliance with the law, as well as implementation of national “best practices.” The manual was mailed to all hospitals and Area Education Agencies in February. The rubric is e-mailed to hospitals prior to the visit so they can conduct a self assessment. All hospitals that participated reported that they liked the tool. It reinforced the areas they were doing real well in and areas they may need further development.

Erin reported that the site visits had been successful thus far. Diana shared that she felt like her staff benefited greatly by having a parent tell their story. It reinforced the work they do everyday. Tammy shared that the EHDI program will be preparing a survey for the hospitals to complete on survey monkey to give feedback about the EHDI Best Practices Manual, rubric, site visit report and visits.

Erin and Tammy asked for suggestions about who should receive the site visit report. Discussion ensued and the recommendation was to include the Director of Nursing and the CEO if hospitals requested they be included. Diana commented that she would be in favor of administration receiving a report, especially one that is positive.

**Audiological Technical Assistance** (Nick Salmon)

Nick provided an overview of the technical assistance he has been providing to hospitals most recently in the form of training, phone calls regarding equipment, etc. Nick talked about the role of he and Emily on the hospital site visits.

Tammy and Nick provided an update in regards to the Early Head Start ECHO Training held earlier in the year. Four Early Head Start programs (serving as pilots) in Iowa were trained on February 25, 2009 and will begin to provide hearing screens to children under the age of 3. Emily, Tammy and Marsha also participated in the “hands on” training by the National Center for Hearing Assessment and Management. Early Head Start programs will be required to submit their hearing screens to IDPH as required by law. Tammy reported that this may help decrease the number of children lost to follow up.
NICHQ (Erin Kongshaug)

Erin shared that Iowa had been selected to participate in the National Initiative for Children’s Healthcare Quality learning collaborative. She explained that the initiative’s focus for this collaborative is on newborn hearing screening and follow up. Because of the nature of the project, Erin is in the process of submitting a request to the Internal Review Board (IRB) at the University of Iowa. Erin provided an overview of projects completed by other states during their participation in past collaborative. The project is funded by the Maternal Child Health Bureau, Health Resources and Services Administration. Iowa will receive a $25,000 increase in their HRSA grant to participate in this initiative over the next year. The money is to cover travel expenses for participants.

Review EHDl Data (Tammy O’Holleain)

Tammy reviewed preliminary newborn hearing screening data for 2005-2007 which included:
- Children screened prior to hospital discharge
- Children who referred on hearing screen
- Children missed prior to discharge
- Home births
- Children lost to follow up
- Hearing loss cases by type

Quality Assurance Indicators (Tammy)

Tammy and Erin shared information with the committee members about quality assurance efforts that occur each month within IDPH to ensure the data is clean, duplicates removed, all babies accounted for in accordance with vital records report and data is correct so unnecessary referrals are not made.

Tammy explored with committee members the idea of a “report card” or “program indicators” report to give to the hospitals that would provide them data about compliance with law, as well as a quality assurance report about data entry, refer rates, miss rates, etc. It may be a report that they could use for quality improvement initiatives. It would also give them an idea where other hospitals of similar size are with these indicators which may serve as motivation (“friendly competition).

Roger suggested we figure out if we want to look at it as compliance (one time event) or something like the rubric (continuous quality improvement) Erin spoke of earlier. Erin commented that other states have something similar that they publish. Lucinda opposed publishing the data. She felt like it was a more punitive approach that would not be well received. She commented that everyone is trying to do their best. She said that you can do all kinds of follow up and some parents do not follow through. Rev. Konkel agreed and added that parents who are Deaf or hard-of-hearing may ignore the requests because they don’t see having a hearing loss as significant of an issue as a parent who is hearing.
Tammy explained that they would be moving to a corrective action plan with hospitals in the coming years for those hospitals that continue to struggle or not comply with the law. Tammy explained that this would be last resort after all other efforts to provide technical assistance were exhausted. Tammy shared that they have worked with some hospitals repeatedly through phone calls, visits and e-mail and the issues continue. She explained that some of the issues have a direct impact on families (unnecessary contact) and timely follow up. They also impact the children who are lost to follow up/documentation. The hospitals will learn about the corrective action plans through the quarterly newsletter and hospital site visits. Stu suggested that the plan for improvement include what it is that will change, date for improvement, measures of improvement and the requirement that both parties sign off on the document. Stu recommended that the EHDI program consider presenting an annual award or plaque during the EHDI Conference or another time during the year. The recognition may be motivation for a hospital or something for them to work towards!

**Sharing**

**Nebraska Parent Conference** (Marsha Gunderson)
Marsha attended the Nebraska EHDI weekend (Roots and Wings) for families of children recently identified with a hearing loss. Information regarding hearing loss, participation in Hands and Voices, communication options and family resources were a few of the topics covered during the conference. Childcare provided for the children. Marsha passed around the folder given to parents. Information included in the folder was information about hearing loss, questions to ask the practitioners they would come into contact with, financial resources available in NE, family checklist, etc. Marsha suggested we look at doing something like this in Iowa either coupled with our conference every other year or opposite years.

Tammy shared that she had talked briefly with the EHDI Coordinator in Nebraska about the conference. Nebraska used carryover monies from one of their grants to cover the costs. However, Tammy and the NE EHDI Coordinator may explore doing something together and applying for a grant.

Tammy suggested that EHDI team members review the contents of their resources to see if anything could be added to the Iowa Family Resource Guide.

**Critical Access Hospital Presentation** (Tammy O’Hollearn)

Tammy shared that she will be presenting to the critical access hospital user group on April 14, 2009. The group is made up of nurse managers, quality assurance personnel, and administrators who work towards quality improvement. Tammy shared that her focus would be on quality improvement and how they could demonstrate quality improvement in their newborn hearing screening programs.

Next meeting: July 9th from 10-3 p.m. at Iowa Lutheran Hospital in Des Moines
Agenda items:  
- eSP Demonstration
- Legislative updates
- Hearing aids and audiological services funding
- Guide by Your Side
- Hospital site visits
- NICHQ learning collaborative