Early Hearing Detection and Intervention Meeting Minutes
July 9, 2009

Present: Roger Hess, Stuart Trembath, Marcy Beisiegel-Clausen, Kathryn Baumann-Reese, John Cool, Marsha Gunderson, Diana Hanson, Bob Vizzini, Barb Khal, Lenore Holte, Vicky Hunting and Cathy Hardy (guest)

Staff: Tammy O’Hollearen, Erin Kongshaug, Nick Salmon, Meghan Wolfe, Brittni Frederiksen (GSIP-EHDI intern)

Announcements (Tammy O’Hollearen)

Early Head Start ECHO Training Project Update (Nick Salmon/Tammy O’Hollearen)
Four Early Head Start Centers are serving as pilot sites (Council Bluffs, Marshalltown, Cedar Falls, and Sioux City) to complete objective hearing screens on children under the age of three. Early Head Start staff was trained in February. Nick reported that approximately 450 kids, ages 0-3 have been screened through this pilot. Nick also reported that Early Head Start staff has been very engaged and responsive. Overall he feels the pilot is going well.

Tammy reported that she has received hearing screening data from three of the programs. She said that one of the programs is confirming with their legal counsel they can share the data with EHDI as required by EHDI law. Tammy noted that many of the kids have passed, but there are a few kids that have referred so the Early Head Start program is waiting to report those results until the final screen. If children do not pass following the referral and treatment by the primary doctor or ENT doc, a referral is made to a pediatric audiologist. Tammy reported that most of the children screened thus far have been in the EHDI data system. Secondly, some kids screened by the Early Head Start program were in the EHDI data system as “lost contact.” Tammy explained that this means that many attempts to reach the family to return for an outpatient screen following birth were unsuccessful. Now because of this pilot, the children were screened.

EHDI Advisory Committee members inquired about future plans for the remaining Early Head Start programs. Tammy said she is waiting to hear from Tom Rendon, Director of Head Start at the Department of Education, with regards to plans to roll this out in other communities. She noted that the Early Head Start programs must consider cost in maintaining equipment, purchasing new equipment in five to seven years and the every day costs associated with disposable tips or probes used in each ear to conduct the screen. Tammy noted that the EHDI program has offered to write a letter of support for the new programs that would need to find money in their budget or through community grants to purchase the hearing screening equipment. In addition, Tammy reported that even though there is expense, Tom has been very positive and expected it to roll out to other programs in the future. Kathryn commented that Community Empowerment may also be a source of funding for the equipment and encouraged providers to consider them as an option.
Tammy and Tom plan to present information about their efforts with this project at the Early Childhood Iowa conference next year.

**NIH Hard of Hearing Grant (Lenore Holte)**

Lenore presented on the NIH Outcomes of Children with Hearing Loss study. The University of Iowa, Boys Town National Research Hospital, and University of North Carolina-Chapel Hill make up the research teams.

Lenore reported that Iowa has recruited 40 kids thus far for the study and overall 150-200 children have been enrolled from all participating states. The length of the project is 5 years. Families do receive a stipend to participate. The study focuses on children who are hard-of-hearing – both unilateral and bilateral, 3 frequency averages of 70 or less. This study does not include hard-of-hearing children with developmental disabilities, however Iowa has sought a supplemental grant so that children with developmental disabilities can participate.

**EHDI Newsletter (Bob Vizzini/Tammy)**

Bob expressed concern over the content of the Spring EHDI newsletter. He said he feels the newsletter seemed one-sided, lacking variety in opinions (specifically lacked sign language view) and he personally found some of the word choices offensive.

Bob said that he would like to see a better balance in news, including articles that provide information about both sides (deaf community vs. hearing community or pros and cons to a particular mode of communication), as well as some news stories about neutral topics. Bob and advisory committee members thanked Tammy for her hard work in producing the newsletter.

Overall the advisory committee likes the look, style and format of newsletters and Tammy reinforced that she is always open to submission of articles for each newsletter. However, she noted that getting articles for the newsletter has been a challenge and to keep in mind that the purpose of the newsletter is to provide education regarding the EHDI program or data base, updates about laws or legislation, share best practices, serve as a mode of outreach to the various communities and share family stories. She noted that the newsletter must reach a diverse audience with different needs and every newsletter is not going to meet the needs of every audience member.

Bob proposed that a subcommittee be formed to assist Tammy in creation of the quarterly newsletter. The following individuals volunteered: Bob Vizzini, Kathryn Baumann-Reese, Lenore Holte, Marsha Gunderson, Vicki Hunting and Marcy Beisiegel-Clausen

The following suggestions/strategies were discussed by the advisory committee as ways to improve newsletter:

- Have a parent story in every edition- want good and bad stories. Include stories from teens and adults, as well.
- If one edition is heavy on one topic have an editor’s comment that next edition will feature other opposing topic/view.
- Parent advice on communicating with child.
o Continue to work on presenting different modes of communication or communication opportunities.
o Focus on literacy development- don’t just focus on the ear for the child.
o Get articles on ASL; may need to go out of state for this information.
o Announcements for stakeholders (audiologists, healthcare providers, early interventionists, and hospitals) will always be a main part of the newsletters.
o Advisory recommended that when Tammy has an article she could sent it to committee to see of other sides need to be represented. Advisory committee can be researchers.

Tammy will send out an email to EHDI newsletter subcommittee to begin planning for upcoming newsletters.

EA-EHDI Data Match (Brittni Frederiksen/Tammy)
Brittni provided the advisory committee with an update of Early ACCESS-EHDI Data Match. She noted that the purpose of the data match is to compare the percentages of children identified with hearing loss in both data bases to ensure they are very similar. In addition, they are looking to find the number of children identified with a hearing loss who are actually enrolled and receiving early intervention services.

Preliminary data indicates that for 2008 95% of children that had confirmed hearing loss are receiving Early ACCESS services. In the EHDI database 37 had determined hearing loss and of that 37, 35 are involved in Early ACCESS. Preliminary 2008 data shows that only 42% that have determined hearing loss are involved in Early ACCESS. Brittini reported that she and Tammy were able to clean up a large proportion of records for 2007, however there is still much clean up that must occur with 2008 data to conduct further analysis. Initial analysis suggests the following: 1) no follow up program is in place for children beyond the outpatient screening, 2) providers are not reporting in a timely manner, 3) all services are not documented in eSP record, 4) many children are not having hearing loss determined, many remain “in process” because providers are cautious when reporting data that will become a part of a medical record, 5) there are data entry errors or incomplete records in both eSP and the EA file, 6) early intervention services are almost never reported to EHDI, which presents a problem because this is something the EHDI program must report back to CDC.

Brittni and Tammy will be meeting with Marsha Gunderson, Educational Audiology, Deaf and Hard of Hearing Education Consultant and Julie Curry, State Coordinator for EA at the end of July or beginning of August to review the initial findings from the data match, analysis and review recommendations and/or “next steps.”

EHDI Law and Administrative Rule Changes (Tammy)
Tammy provided the advisory committee with an update on where things stood on the amendments to the EHDI law and the proposed changes in Iowa administrative code for the EHDI program. She noted that the amendments to the EHDI law were signed by Governor Culver in April and they took effect July 1, 2009. The changes include:

• Hospitals required to report risk factors associated with hearing loss
• Hospitals required to report newborn hearing screening results to PCP in writing
Clarifies language regarding reporting of primary care provider (required to report child’s primary care provider they will see upon discharge for well child check ups; not hospitalist)

Audiologists and other healthcare providers must report all screens and diagnostic assessments to the Department within six days

Rules added to provide guidance for the Hearing Aids and Audiological Services Funding program

Administrative rules have been noticed and are open for public comment. Written comments are being accepted through August 4, 2009. A public hearing will also be held on August 4, 2009 by phone. This information is included in the notice. The rules will go into effect November 1, 2009. Tammy stated that all licensed individuals will get notification of new rules changes via mail. Tammy will also email noticed rules to advisory members again to distribute to their colleagues.

NICHQ/HRSA Grant Updates (Erin Kongshaug/Diana Hanson)

HRSA Grant Update. A grant application for supplemental funds was posted with a due date of June 22. Iowa submitted an application. The focus of grant is on preventing children from becoming “lost to follow up/lost to documentation.” Erin stated that HRSA is looking for activities that would make a big impact right away. Erin reported that they expect that approximately 57 grants will be submitted and only 40 will receive awards. Funding is for two years and would begin September 1, 2009. Iowa applied for approximately 150K for each of two years. Iowa’s application focused on developing a comprehensive follow up model in one region of the state, and spreading successful strategies to other regions. Grant funds would also be used to purchase a hospital an AABR unit and to purchase OAE equipment for Child Health Specialty Clinics (CHSC). The EHDI program will work with regional stakeholders to develop a comprehensive follow-up program that includes care coordination to help schedule rescreens and diagnostic assessments, assure documentation of the results in the EHDI database, and refer to Early ACCESS, and family support programs when appropriate. CHSC will recommend that this care coordination be provided by CHSC parent consultants. The CHSC EHDI program will also explore the possibility of using telehealth in the audiology field to make diagnostic assessments more accessible. Grant funds would also be used for outreach to Latino communities, and to hire a bilingual parent consultant. Funds would also be used to purchase a case management component for eSP.

NICHQ Update. Erin reported that the team went to Atlanta in May for first the first learning session. There was pre-work that also needed to be completed prior to the first session. The NICHQ Team had the opportunity to meet with other states, learn about the PDSA Model and had the opportunity to work with coaches for one-on-one assistance. NICHQ team members at the EHDI meeting stated that they would have preferred more time at the session to work as a team and utilize the coaches for project planning and implementation.

Iowa has begun implementing small tests of change at Iowa Health – Des Moines (including Iowa Methodist Medical Center, Iowa Lutheran Hospital and Blank Children’s Hospital). One PDSA is looking at who was recorded in the health record as the child’s primary care provider and comparing that PCP with who the family reports to the screener at the time of the hearing screen. This is important
to assure that PCPs know what the newborn hearing screen results were and which children need further follow up. A second change being tested is how quickly a follow up appointment can be scheduled for a rescreen. Diana reports working with 20 families and so far 10 of those children have come in within two weeks for the re-screen. A third small test of change that is being proposed is to develop a written script for RNs/techs to use when talking with families about the importance of a rescreen. In addition, there is also discussion about putting together a family information packet with family support services and community resources. One of the resources to be developed is the Hearing Healthcare Map. Tammy explained that Iowa likes the lay out of the map developed by Colorado. The Advisory Committee spent the remaining time developing Iowa’s map. The committee decided that Iowa should have two maps for families (1-3 month map and 3-6 month map) as well as a map for physicians. Tammy stated that she and Brittini would take the suggestions from the committee and send them to the individual who is designing the map. Once there is a draft, Tammy will disseminate for comments.

Hospital Site Visit Results (Tammy/Erin/Nick)
Tammy quickly went over the survey monkey results from hospital site visits. Four people have completed the survey and the results were positive. It appears all felt the hospital visits were valuable and a good use of time.

Tammy provided some brief comments about the site visits thus far. She noted that the visits will continue. Each hospital receives a written report with a summary and recommendations. Best practices that the EHDI program learns about from the visits will be highlighted in the EHDI newsletter.

Guide By Your Side Program (Erin)
Erin will send out Melissa Carlson’s Guide By Your Side Program update to Advisory members via email. The committee discussed underutilization of the program. Erin stated that marketing efforts have focused on educational audiologists, which has not proven to be a successful strategy. Marsha stated that the teachers of students who are Deaf or hard-of-hearing can/should also make referrals. May need to contact those providers again. The committee discussed need for diagnostic centers to begin referring to program. Stuart talked about the need for audiologists to have a checklist similar to the map which would include a referral to the GBYS program.

Hearing Aids and Audiological Services Funding (Tammy)
Tammy reported that the program received funding for 1 more year. The funding amount has been decreased by about 40K but will continue to pay for hearing aids and audiological services for children under the age of 21. She noted that she will no longer be enrolling families. Provider Claims Systems will take over this responsibility to free up some of Tammy’s time and provide additional care coordination. IDPH will still be responsible for payment authorization. Tammy reported that the funding announcement, application and frequently asked questions guidance for the Hearing Aids and Audiological Services Funding has been updated on the EHDI Web site. Tammy and Lori (from Provider Claim Systems) will be updating the issue brief for legislators this fall. Tammy is soliciting quotes from parents who have benefited from the program to include in the issue brief. Tammy asked that committee members send her parent quotes for those children who have accessed the funding by middle of August.
eSP Demonstration (Tammy)
Agenda item tabled. Group used time to focus on the development of Iowa Hearing Map.

Wrap Up-Agenda Items for October
- Newsletter Committee
- HRSA Grant update
- eSP Demonstration
- Data integration efforts
- EA-EHDI Data Match
- CDC Report

Next Meeting is October 1, 2009 at the Altoona Public Library.