Early Hearing Detection and Intervention Meeting Minutes
October 1, 2009

Present: Roger Hess, Marcy Beisiegel-Clausen, Kathryn Baumann-Reese, Jeffrey Hoffman, Marsha Gunderson, Diana Hanson, Bob Vizzini, Barb Khal, Debra Waldron, Vicky Hunting, Amy Wallin, Ben Kirby, Lucinda Hollingshead and Donald Miksell

Staff: Tammy O’Hollear, Erin Kongshaug, Emily Andrews and Meghan Wolfe

Announcements
- Marsha shared with the committee member’s information on ordering a newly released book titled, The Book of Choice.
- Don shared that the next Iowa Association for Deaf meeting is being held on October 31, 2009 in Council Bluffs.
- Erin Kongshaug announced that this is her last meeting as she is resigning from her position at CHSC as EHDI Follow Up Coordinator; she will be a fulltime mom.
- Joan Marttila announced that this is her last meeting as she is retiring at the end of December. Tammy and Joan will work together to find a replacement to represent AEA audiologists.
- Tammy presented Joan a plaque for her service to deaf and hard of hearing children.

EHDI Law and Administrative Rules Changes (Tammy)
- The law changed in April and went into effect July 1, 2009. Administrative rules were written and published for public comment over the summer. Tammy reported no public comments were received. The rules were approved by Iowa Department of Public Health, Board of Health and go into effect November 11, 2009. The summer edition of Iowa EHDI News highlights the changes.

Winter Newsletter (Bob/Tammy)
- Committee was formed and had first meeting October 1, 2009.
- Committee discussed creating sections in the newsletter and will be sending out a survey on survey monkey to recipients of newsletter for input on content.
- Discussed articles to be included in the Winter newsletter:
  o Plan to feature family support group “Strength in Numbers”
  o Bob plans to write an article about ASL and culture.
  o Marsha and Marcy to work on article on the characteristics of families of successful children
  o Information regarding Early ACCESS and EHDI data match
  o Article on lost to follow up
Hearing Aids and Audiological Services Funding (Tammy)

- In the fall newsletter, that can be obtained online, there is a summary of how funds were spent last year. 15% of the funds were spent on hearing aid and audiological services for children 0-3 years of age, 71% on children 4-15 years of age and 11% spent on children 16-20 years of age.
- Tammy shared that the Child and Family Policy Center has taken an interest in the issue of health insurance companies providing coverage of hearing aids and services. The Child and Family Policy Center may approach Wellmark Blue Cross and Blue Shield to see if they will add hearing aids and audiological services to their covered benefits under their plans. Tammy noted that a small number of Wellmark Blue Cross and Blue Shield plans do provide hearing aid and audiological services coverage because the employer has included that in their benefit package.
- Tammy reported that Wellmark Blue Cross Blue Shield was the largest health insurance provider to the children who received Hearing Aid and Audiological Services Funding who did not have hearing aid and/or audiological services coverage.
- Approximately 13 states have hearing aids as a mandated coverage benefit now. Tammy reported that the Child and Family Policy Center feels that Iowa will have better luck at the national level than the state level in getting these items added as a covered benefit.
- Joan stated Iowa Speech Hearing Association (ISHA) has a long standing committee that has worked with Wellmark Blue Cross Blue Shield on reimbursements, etc. She suggested that the Child and Family Policy Center may want to contact them for support.
- Barb discussed Early Childhood Iowa is going to feature children stories for Day on the Hill. Barb recommended a deaf or hard of hearing child’s story be present at Day on the Hill.

AABR/OAE Screening/Re-screen Issue (Diana/Erin)

- EHDI follow up sends letters to children’s primary care physicians (PCP) and parents regarding the need for rescreens. The EHDI follow up letters recommend AABR outpatient screening (in accordance with JCIH) for NICU graduates and babies who received an AABR screen and did not pass prior to hospital discharge. Erin shared that the concern is that AABR outpatient screenings are not readily available across the state. Many parents would have to travel to obtain this type of screen.
- Diana Hanson, as an audiologist, has concerns regarding the recommendation from JCIH. Diana feels that in theory the need for an AABR rescreen is valid, but feels that in only doing an AABR screen, some children’s mild hearing loss may be missed. Need to recognize that OAE screens also have a benefit. Diana noted that auditory neuropathy is rare.
- Lucinda states that on behalf of Mary Greeley they are not able to bring children back to nursery for AABR rescreen therefore she feels the AABR rescreen is a difficult recommendation to meet.
Tammy reviewed the small number of hospitals that have the capability of performing AABR screens and an even smaller number who are willing to bring children back. She reported that the EHDI staff continues to encourage hospitals to bring the children back for the outpatient rescreen. Outpatient rescreens have proven to be the most effective when completed at the birthing facility. Families avoid lengthy travel and they have a certain comfort in coming back to the place they gave birth. In addition, most of the children pass the screen and do not require additional follow up.

Joan agrees with Diana Hanson’s view. Joan wonders if there are AEA facilities that have the capacity to do AABR if the AEA could look into contracting with others to provide AABR for children who do not need sedation. Emily echoed the concern we are losing children and missing hearing loss due to the lack of AABR rescreen providers across Iowa. Roger asked about the AEAs’ current capacity to provide AABR rescreens. The group was informed that AEA 9 and GPAEA are able to do AABR rescreens. Roger states that AEAs are currently working to ensure hearing screening booths are located so that families have no more than a one hour drive. Roger stated that they may be able to explore the AABR issue once they secure the hearing booths.

Feedback was requested for content changes in the EHDI follow up letter that is sent to PCP and parents. Erin will take group input and revise the letter. The letter will be sent to Diana, Vicki, Debra and Emily for final approval. Bob expressed concern over use of “child did not pass test”. Dr. Hoffman suggested stating that the baby “needs a rescreen” rather than using “did not pass” or “referred.”

Diana states screening AABRs can be completed on babies without sedation probably up until 60 days old- this statement will be included into EHDI follow up letter to express importance of timely rescreen.

(NICHQ) National Initiative for Children’s Healthcare Quality (Erin/Diana)

- The focus of the NICHQ project is to reduce the number of children lost to follow up. Iowa first focused on improving the rescreen process and next the focus moves to timely diagnosis.
- The NICHQ team is scheduled to meet with Mercy-DSM and Heartland AEA to work on getting children in for a rescreen before 1 month of age.
- Diana shared the small tests of change Iowa Health has done during their time with this project .
  - Their first test was to verify the PCP with the parent report and compare to the PCP listed in the medical record. Now they are verifying PCP on babies who refer on newborn screen by contacting PCP office directly and informing PCP of results.
  - Second test, is that newborn screen staff fills out EHDI referral form which is given to parent and then given to scheduler to get parents back in. 4 no shows out of 69 babies born who were scheduled that way. Second cycle- reminder calls regarding hearing rescreen appt. Reminder call has proven beneficial. Of 69 babies who referred 98% have come back in within 30 days. Outcome is to share this practice/success with other hospitals. They will try scheduling appointments before discharge in the next cycle.
Iowa’s Early Hearing Detection & Intervention (EHDI) Program

- Diana reported that their next small test of change is blocking off time in her schedule for AABRs to see if that will reduce the 3 week wait for a diagnostic AABR.

**Iowa Symposium for Hearing Loss: Impact on Children & their Families (Emily)**
- Emily passed out the program from last symposium held in 2008.
- Emily reported that Lenore received an award of $18,500 grant to hold the symposium. The symposium will be held at the Marriott in Ankeny on September 17 & 18, 2010.
- Emily said that a meeting will be held in the next month or so. They hope to have the national speakers secured by end of the year. The committee is waiting to learn who the national EHDI speakers will be. Vicki is on the National EHDI planning committee and will share speakers with Emily and Lenore as soon as she hears.
- Committee members interested in assisting in conference planning, please contact Emily or Lenore. Any ideas for speakers or topics, contact Lenore and Emily.
- Barb expressed the like of panels of parents or deaf and hard of hearing teenagers at symposium. Those sessions were well received and attended.

**HRSA Grant Updates (Erin)**
- CHSC received a HRSA stimulus grant that began on September 1, 2009!! It will result in a significant increase of funds until 2011. Erin reported that the goal of the grant was to decrease the number of children lost to follow up and do it quickly. In year one, the EHDI program plans to upgrade the eSP database to include a case management component. In the first 6-12 months, HRSA grant personnel plan to do outreach work with Hispanic population. They have also budgeted for a couple OAE screeners for Child Health Specialty Clinics regional programs so that personnel can go into the homes of families who have transportation issues. One screening AABR will be purchased and placed in one region that does not have this equipment readily available. They will pilot using the equipment for outpatient re-screens. HRSA personnel will decide on a pilot region by January 2010.
- Joan wonders if the EHDI program should be requesting state funds from the Iowa Legislature. Tammy said that she thinks that is something that we are all working towards, but now is not a good time. She feels that the EHDI program needs more information from the small tests of change and the program evaluation that is scheduled to be conducted in the next year. At that time, she feels the program can then put a plan in place and talk to the legislators about the system needs related to sustainability.

**GBYS Guide By Your Side Program (Group Discussion)**
1. Melissa Carlson is the family support coordinator and parent coordinator for GBYS. Erin shared that the program continues to be underutilized. Erin reported that those parents who have been involved have reported being satisfied with program. The program provides families of children who are deaf or hard of hearing with Guides. The Guides are parents of children who are deaf or hard of hearing or are adults who are themselves deaf or hard of hearing. At this time families involved in the program have selected parent guides and have not utilized deaf or hard of hearing guides.
How has the program been advertised? Erin shared that she and Melissa have visited six to seven AEAs and have participated in an ICN for the parents who are a part of the Parent Educator Connection. Some children were identified through EHDI database. Vicki tried cold calls, but those calls proved unsuccessful.

The committee discussed ways to increase awareness of GBYS, ideas included:
- Assure GBYS is represented on the internet. Get GBYS on YouTube and Facebook.
- Partner with the Department of Education. DE is working on recruitment tool for new staff.
- Get GBYS brochures in audiologist offices, AEAs across the state.
- Feature parent stories in EHDI newsletter.
- Develop a checklist for audiologists and early interventionists providing service coordination to deaf and/or hard of hearing children. This would serve as a reminder to those working with the families to make a referral. The checklist would contain a step of “make referral to GBYS”.

The committee had a discussion regarding the timing of referrals. A few members feel that parents should definitely have to “opt out of a referral” - don’t present it as such a choice. Iowa Health discussed trying a small test of change where audiologist would automatically refer a family to GBYS and family has to opt out. Before small test of change begins, Dr. Waldron would like to assure providers have the “right” to automatically make it a referral that a family would have to “opt out”.

Dr. Hoffman asked whether the GBYS program would have the capacity to potentially serve the estimated 120 newly identified deaf or hard of hearing children. EHDI staff informed him that Iowa does not have capacity to serve all 120 children; however program is currently under utilized and could serve many more children than are currently being served.

eSP Demonstration (Tammy)
Tammy provided a demonstration of eSP (eSCREENER Plus), which is the EHDI data base. She demonstrated how hospitals and audiologists use the data base.

Agenda Items for January
- EA/EHDI Data Match
- GBYS follow up
- Hearing healthcare directory
- NICHQ
  - Pilot region chosen
- Hearing Aid and Audiological Services Funding update
- Symposium update
Next meeting is January 7, 2010 via ICN.
Requested ICN locations:
- Emily - CDD
- Dr. Hoffman - Clayton Ridge HS
- Bob - Kirkwood CC
- Kathryn - IDPH
- Marsha - Iowa School for Deaf
- Marcy - Muscatine CC or HS.
- Lucinda - Ogden HS
- Val - Creston AEA