Early Hearing Detection and Intervention Advisory Committee Agenda
Thursday, April 5, 2012
10:00 am – 3:00 p.m.

Location: Hoover State Office Bldg, A level, Rm 7

Members Present: Marsha Gunderson, Diana Hanson, Steve Sword, Sara Lincoln, Jill Simonson, Linda True, Sally Nadolsky, Valorie Caputo, Marcy Beisiegel-Clausen, Amy Timmerman, Michelle Vaccaro, Emily Andrews, Shannon Sullivan, Kathy Miller, Jacquelyn Hackbarth (audiology student)

Staff Present: CHSC: Vicki Hunting, Susan Hagarty, Grace Cervantes. IDPH: Tammy O’Hollearn, Esha Steffen, Sylvia Petersen (EHDI Intern)

Introductions & Announcements
Members introduced themselves. Announcements included:

- New EHDI Staff: Grace Cervantes, Long-term Follow up Coordinator
- Announced new members to the committee, Linda True replacing Stuart Trembath for private audiology/ENT clinic, Mary Stevens will replace Grace Bargstaat as AEA Director, Teresa Hobbs will represent Early ACCESS. Sara Lincoln, NW AEA audiologist is filling in for Teresa at this meeting.

Iowa Symposium on Hearing Loss/National EHDI Conference (Iowa EHDI Team)
Iowa Symposium
- Sept. 28-29
- Brochure will come out at the end of April
- Round tables need to be finalized to be included or they will be included in packets given at symposium
- Speakers secured

National EHDI conference in St. Louis, MO
- Shannon—found the sessions discussing the challenges in identifying high-risk children on EMR interesting and helpful—how physicians, clinics and schools can target high risk children; best approach to follow them so they don’t get lost; data on subgroups of particularly high risk kids
- Esha—found the Oklahoma session on how they reduce refer rates to be very interesting.
  - OK trying to turn 1-3-6 months into 1-3-6 weeks; OK are coming to Iowa this spring. Esha interested in learning about their short term follow up efforts and continuing to improve miss/refer rates in Iowa.
• Educating physicians and nurses through CMEs. Need to figure out what education they need, as well as nurses and screening staff.

• Marsha—attended session on communication plans for Part B; not explicitly stated in Part C
  ▪ Marsha attended the National Summit on Deaf Education—explored what the national agenda for deaf/hard-of-hearing students do in the area of outcomes and indicators
  ▪ Marsha spoke on transitioning from Part C to Part B—She noted people were really excited about the workshop and she felt not all systems across US are as good as ours

• Kathy—surprised by the small number of deaf people there
  ▪ All sessions were good (more workshops in the future)

• Jill—surprised by the high numbers of people signing
  ▪ Felt breaking off into states made it more personal, chance to meet other persons from state
  ▪ Jill working with ENTs at her clinic to meet 1-3-6 goals. Found the conference informative

• Jacquelyn (Audiology Student)
  ▪ First time attending national EHDI Conference
  ▪ Great learning experience

• Vicki—found information on the importance of social media in message of EHDI
  ▪ Discussed the large turnout for national conference and the presence of more international persons (Canada, Italy, Australia)

• Susan—noted there were a greater number of parents this year and each year she attends. Noted they easily identified through tags. Also found the tags useful in locating those persons who can sign, etc.
  ▪ Breakout session—use of deaf and hard-of-hearing mentors in GBYS programs
  ▪ Grief process—higher level of awareness of emotional issues in children with hearing loss and their parents
  ▪ Parent choice—how do you know when you’re making the right choice

• Tammy—attended sessions on engaging home births families and decreasing the number of children lost, state strategies, etc.
  ▪ Tammy talked about a home birth project one of Lenore’s students will be doing over the next two years in an attempt to educate providers so they can educate families and also on engaging those families in the screening process
Tele-Audiology Learning Community (Emily/Vicki)
- Vick & Lenore will be representing Iowa in a Tele-Audiology Learning Community hosted by NCHAM. The purpose of the learning community is to bring together those who are pursuing the use of telehealth technologies to provide direct diagnostic and other audiological services for children with or at risk for hearing loss. The learning community will provide an opportunity for participants to learn from one another, share successful strategies, and to work together to address challenges. The information and products resulting from the learning community will be disseminated to NCHAM’s broader audience in our efforts to support the provision of appropriate tele-audiology services. This learning community is similar to the work NCHAM did in creating the guide for Tele-Intervention in providing listening and spoken language services to children who are deaf or hard of hearing.

- List of desired outcomes for learning community:
  1. Gain new knowledge about tele-audiological technologies.
     • Equipment, systems being used
     • Strategies to address security
     • Portability of equipment
  2. Understand the importance of “the human factor”
     • Building partnerships with stakeholders
     • Ensuring positive interpersonal interactions with families
  3. Articulate the key steps of the process to develop tele-audiological services:
     • Organizational Readiness
     • Facility/Site Assessment, budgeting
     • Program implementation: Administration, technical support, clinical procedures
     • Data Collection to measure outcomes
     • Sustaining & spread of your effort
  4. Research solutions to address challenges impacting tele-audiology, specifically licensure and reimbursement
  5. Identify tools to measure costs and effects of your tele-audiological services.

EHDI Chapter Champion Update (Dr. Sullivan)
- Shannon reported she is focusing on educating physicians and other healthcare professionals
  - Grand Rounds presentation in Iowa City (9/2011), Blank (04/2012), Mercy Des Moines (10/2012)

AAP Project Updates (Vicki)
- EHDI MOC Project: Ensuring follow-up for children at risk for delayed-onset or progressive hearing loss (HL)) is on hold while CHSC EHDI goes through University of Iowa Institutional Review Board (IRB). No new start date is available at this time.
EHDI AAP Chapter Education & Training Grant is progressing and ends June 30, 2012. Goals for the project include: 1) increased PCP knowledge on EHDI and the IA-EHDI SOC; and 2) increased linkages between the clinical care system (PCPs) and the family support/care coordination system. This will be achieved through the creation, coordination, and dissemination of a multi-media educational message for IA PCPs around the IA-EHDI SOC. Pediatric Grand Rounds complete at University of Iowa in September 2011, April 6, 2012 at Blank Children’s, October 2012 Mercy Hospital. Materials distributed include resources available from AAP EHDI Guidelines for Pediatric Medical Home Providers, Iowa EHDI Resources.

Loss and Found Video (Vicki/Susan/Tammy) – Professional video completed. Work group made up of parents and professional staff. Video used by a few other states. Will be loaded to the Hands and Voices website, as well as EHDI website. Will notify committee members of link when available. Vicki played video.
  o Workgroup working on distribution list. 500 copies to distribute. Additional items also included in the EHDI Toolkit: Letter from Dr. Waldron and Gretchen Hageman, State Title V Director (explaining what toolkit is for, why it is important), Loss & Found video, posters from NCHAM & CDC, Early ACCESS brochure, GBYS brochure, lanyard, flash drive, contact card. Work is also in progress to evaluate the effectiveness of the materials. Technical Assistance from AAP has been requested.
  • Vicki noted that the notecard emphasizes that undetected hearing loss is a developmental emergency
  • Video used to educate parents, PCPs. Spanish version with subtitles also available.
  • Question from committee member asking why the AEA’s were not given as the primary contact. Explained that Early ACCESS Iowa number is given. EA Iowa trained to provide families with all the options for providers in their area (AEAs, CHSCs, hospital outpatient clinics, audiologists). The staff is also bilingual. Family may be in need of more than just a hearing screen.
  • Question from committee member inquiring why the physician was not recommended as the contact. Vicki noted that the PCPs/medical home are often comfortable in discussing results, but they often do not know where to refer parents and they also sometimes do not stress the urgency of follow up. The information going out to the PCPs should help them with this and they should become more comfortable providing the information in the future.
  • Suggestions for distribution of videos: Prenatal classes, developmental courses
Val stated that she doesn’t feel the AEAs are getting referrals soon enough. Tammy reported that the AEAs are getting referrals the fastest they have ever received them from Iowa EHDI. She also explained that the families and PCPs are being notified at the beginning of the process before the AEAs ever receive referrals. She also explained that AEAs are no longer getting unnecessary referrals that they had in the past (hospital forgot to enter the results, etc) which has actually decreased some AEAs workload quite a bit and has allowed them to focus on the parents who said they were going to call the AEA or had already made an appointment.

Tammy stated that the AEAs can still search for kids and don’t have to wait for the list so long as the hospital has added them as a provider (hospitals would have had to obtained consent from the parents as some parents choose to go to another provider for the screen).

Vicki discussed distribution to hospitals and how the program would be encouraging those hospitals with a newborn channel to include the Loss and Found video as an option.

Guide By Your Side (Susan)
- Susan reported meeting individually with guides to train. Gives her a better idea of what the individual needs for training
- Mandatory reporting training will be a required training
- Same rate of referrals
- Important for audiologists to remind families about family support because they have other things going on in life outside of dealing with services, decisions, etc; they may be overwhelmed

Social Media Updates (Vicki/Tammy)
- Iowa Hands & Voices has a new website (http://iowahandsandvoices.org/) for parent support that includes membership information, photo gallery, newsroom
- Find Iowa H&V on Facebook: Iowa Hands & Voices
- Follow Iowa H&V on Twitter: @IAHandV
- GBYS-new email address: iowa-gbys@uiowa.edu
New EHDI Logo (Tammy)
- In the process of changing logo. Will have an updated look. Tammy to send out to EHDI advisory members for feedback

Redesign of EHDI website committee work (Tammy)
- Tammy noted that Iowa was selected as a finalist for the national award for websites at the same time they made the decision to redesign the site. Tammy noted that the site that was chosen this year is targeted more to professionals and noted it is a little busy looking. She noted that when she started in January 2006, the site had two pages. In fall 2006, the site was expanded to include a professionals page, parent page, advisory, home page and national and state links with many resources on each page, but many restrictions on design. Each year more content has been added. Tammy noted we continue to have good information, but have outgrown the design. She stated we need to make it more professional looking and user friendly.
- Tammy met with IDPH IT and many of the restrictions in place in 2006 have been lifted. Tammy noted the goal is the same; make it user friendly for both parents and professionals. She noted they also plan to incorporate and emphasize the 1-3-6 goals.
- Committee members provided feedback about a possible home page design. The committee then broke up into two groups; one professionals and one group for parents. Notes were gathered about possible design, layout and content for the parents and professional page, as well as home page. Tammy will email out the design template or bring it to the next meeting so committee members can ensure the layout and design is what they had in mind.

Charter/membership/committee work groups (Tammy)
- Tammy said the EHDI team is looking for more volunteers for other work groups that will be established in the coming year, Best Practices Manual/Protocols (Diana Hanson, Lenore Holte, Emily Andrews, Val Caputo, and Linda True), Administrative rules (Marsha Gunderson, Lenore Holte, Emily Andrews, Vicki Hunting)
- Charter
  - Tammy asked if there were any final questions regarding final version of charter
  - Need signed copy from each member

Wrap Up/Sharing
- **HRSA EHDI Grant (Vicki):** Notification from HRSA has come reducing our grant award by 10% ($30,000) for period April 1, 2012 – March 31, 2013. Work is in progress to determine how this reduction will be handled. No official information on whether or not we will be able to request carryover of unobligated funds.
Texting (Marcy): Marcy noted they are using texting to communicate about audiology and other appointments at their AEA’s if the parents provide that information when first scheduling.

Participation in a Community of Learners from National Center for Cultural Competence (NCCC), and the National Center for Hearing Assessment and Management (NCHAM). Six teams from the states/territories of California, Guam, Iowa, New Jersey, West Virginia and Wisconsin has been selected to participate in the Community of Learners initiative. This work will focus on leadership to advance and sustain cultural and linguistic competence in EHDI programs. Participants from Iowa on the team that travels to Washington, DC: Grace Cervantes/Project Lead, Susan Hagarty/Parent, Kathy Miller/GBYS & Community representative. Iowa non traveling team participants include: Vicki, Tammy, Hector Garrido, Anne Crotty/CHSC, Shannon Sullivan, MD, a pediatric audiologist, and representatives from Early ACCESS and AEA. If you are interested in participating on the sub-team contact Grace Cervantes, grace-cervantes@uiowa.edu or 319-356-3570.

**Agenda Items for July**
- Expanded Core Curriculum for Students Who Are Deaf or Hard of Hearing (Marsha)
- Update on EHDI Website
- Hospital reports—refer/miss/follow-up
- Update on EHDI Logo
- Data on last year’s hearing aid funding use

*Next EHDI Advisory Committee Meetings: July 12 and October 11; 10-3 p.m., Location to be determined and announced via email*