Early Hearing Detection and Intervention Advisory Committee Meeting Minutes
Thursday, July 12, 2012
10:00 am – 3:00 p.m.

Location: Altoona Public Library, 700 8th Street Southwest, Altoona, IA

Members Present: Marsha Gunderson, Diana Hanson, Jill Simonson, Linda True, Sally Nadolsky, Valorie Caputo, Marcy Beisiegel-Clausen, Kathy Miller, Lenore Holte, Lisa Zager (audiology student), Teresa Hobbs, Jill Avery, Mary Stevens, Patrick Clancy, Barb Khal, Dr. Eytan Young, Gretchen Hageman

Staff Present: CHS: Vicki Hunting, Susan Hagarty, Phyllis Wood, IDPH: Esha Steffen, Sylvia Petersen (EHDI Intern)

Introductions & Announcements
Members introduced themselves. Announcements included:

- Staff resignations: Grace Cervantes (Long-term Follow up Coordinator); Hector Garrido (Hispanic liaison for Guide By Your Side)
- Announced new members to the committee: Jill Avery (Iowa Department of Human Rights) & Patrick Clancy (Superintendent of the Iowa School for the Deaf)
- Esha provided an update for IDPH
  - Tammy and Esha have been working on the CDC iEHDI file over the past several months. The purpose of this project was to obtain a limited set of existing, individual level data with a defined set of fields that included four consecutive quarters of data from a minimum of six states. Iowa was one of the six states that participated in this project. The file was submitted to the CDC on June 29th, 2012.
  - EHDI website is still in process. A new logo should be selected soon!
  - EHDI Newsletter was skipped for Spring 2012 because of other high priority projects (CDC file) that were time-sensitive at the same time.
  - The CDC EHDI team will be conducting a site visit on August 29-30th

Expanded Core Curriculum for Students Who Are Deaf or Hard of Hearing (Marsha)
- Marsha provided an overview of the Expanded Core Curriculum (ECC) for Students Who Are Deaf or Hard of Hearing
  - This is expanded curriculum containing everything children need to know in school that is missing for children who are deaf or hard of hearing. It contains knowledge and skills unique to these children.
  - ECC was originally identified for the field of vision loss, expanded in the mid 1990s, and developed for students who are deaf or hard of hearing in 2005.
The ECC includes 8 content areas that teach and improve knowledge and skills in addition to general curriculum. The curriculum can be found on the Iowa Department of Education website. These content areas are broken down into a hierarchy including skill areas, subskills, and targets for each area. For example: Family Education; Skill Area: Family & Child Interactions; Subskill: Cultural Awareness; Target: Parent is aware of parent behaviors and infant characteristics that lead to positive parent-infant relationships.

All students are expected to participate and to be integrated with all peers, including those with full auditory access. The ECC is not state required, but is used by teachers of the deaf and hard of hearing as well as educational audiologists.

Q. Why is there not an effort to make this a requirement?

A. It tends to end up on the one person working on the state level. There are also many other state requirements to keep track of. Currently, people are using it as much as possible but it is not on the forefront.

ECC Discussion:

- Susan—ECC can be used in mastering skills for students’ own technology. They can teach teachers to use it, know when it is not working and how to fix it or who to talk to in order to get it fixed. This works very well with individual education programs (IEPs).
- Valorie—it also works with high functioning students who have met their IEP goals. These students would normally be sent out into the mainstream and not receive additional support, but ECC is a good way for them to still receive support. It is documented through the State of Iowa as well.
- Hands and Voices should educate parents on ECC as well; some parents may think they already know. It is very helpful when parents come to the IEP meeting and say “this is what’s going on with my child”.
- Vicki—it is important for those working with deaf and hard of hearing students who assume they hear everything but do not really know how they are getting access to what is going on. This helps with other roles in the education system. It is important to promote ECC wherever possible, e.g. social media.

Deaf Child Bill of Rights (Kathy Miller)

- Kathy provided a brief history on the Deaf Child Bill of Rights (a copy will be sent out to the committee members via email)

- It was introduced in March of 2010
- Talked about education needs for children with hearing loss
- It was reduced from three pages to one. The bill died and was later reintroduced.
Currently, we are working to enhance the bill and get it back to three pages; they set up a meeting in May and talked about the bill and how to improve it. It is now three pages and talks about communication access for all deaf and hard of hearing students, as well as equal access in school. There is an open meeting on August 4th at the Altoona Public Library to discuss the modified bill. They are hoping parents will attend to assist in making modifications. Hoping to address the legislative committee this fall.

Discussion

Q. Does the bill talk about equal access in settings other than school?
A. It covers access in schools for children—expanding would make the bill much more complicated. Because it has been a struggle to get the bill through while narrowed down, it would be even more difficult if it were expanded.

Q. Has there been any research on other states who have the bill to see what might be missing in Iowa?
A. They went to the National Association of the Deaf and looked at 11 states where the bill has been accepted.

Cultural Competence Community of Learners Update (Susan)

Susan provided examples of issues in cultural competency while working with families

- Issues may appear as noncompliance but are actually culturally based
  - Hispanic families who do not have legal status
  - Families in government supported or subsidized programs
  - A phone call was made to a family who had a language barrier (mother did not speak any English, father spoke only a little); they had cancelled an appointment and did not reschedule because they believed they would be contacted. In their culture, they would not assert themselves with professions or initiate contact
  - Cultural awareness helps us effectively serve families and take care of babies

Meeting in Washington, D.C.

- Guam, IA, CA, WI, AZ, and NJ participated
- Each state set up their own goals and how they will meet them
- Iowa is different in that the EHDI program encompasses both IDPH and CHSC so we are going very high up within the framework to implement cultural competency.
- Deaf culture was discussed. This was an important conversation to have and was valuable to explore as a group containing different states as well as two deaf adults
Kathy felt learning about cultures in general was extremely valuable, as well as discussing mutual respect.

The meeting provided tools to educate others

- It is important to identify cultural subgroups within the state we can connect with.
- Sponsored by NCHAM and the Center of Cultural Competencies in Washington, D.C.
  Project will end next May

Discussion:

Q. Would cultural poverty be addressed?
A. It is important to determine what is the most effective way to involve the family, as well as going through the correct channels. It is important to learn first before adjusting the approach to families. (Jill Avery is working on intersecting deaf and hard of hearing, disability, and Native American populations)

Q. Will this pertain to all EHDI groups?
A. Yes—the work will focus on EHDI programs being culturally and linguistically competent

Tele-Audiology Community of Learners Update (Lenore/Vicki)

Access to qualified pediatric audiological services is a challenge for many families, especially those in rural areas. The purpose of this 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. This 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.

Participants:
1. California
2. Colorado
3. Canada
4. Iowa
5. Tennessee
6. Wisconsin
7. Utah

Each state shared info/video of their Tele-Audiology setup (process, equipment/setup). We shared a (amateur) video of the TA site in Iowa City/CDD and Oelwein CHSC Regional center
that gave participants a feel for the setup. We are very fortunate in Iowa to have a static location for our equipment in a quiet controlled environment. Some states have trouble finding a place that is quiet and out of the traffic pattern to do their tests. Something to consider as we figure out how we might use this in other parts of Iowa.

**Topics of discussion included:**
- Elements of High-Quality Infant Diagnostic Evaluations
- Training of staff
- Equipment and connectivity
- Privacy & Security
- Licensure & Reimbursement—this can be difficult; currently it is under the scope of The University of Iowa Hospitals and Clinics, but once expanded reimbursement could be a major obstacle
- Understanding the “human factor”—the difference between face to face and virtual care; should the people on the other end deliver the diagnosis or via tele-audiology
- Measuring cost – effectiveness
- Next Steps for LC: develop work plan for the Learning Community

**What will we look into further for Iowa:**
- How do we transport the equipment should we take this on the road?
- Document our policies, procedures and processes
- Train more people?
- Get in touch with/collaborate with other Tele-med programs @UI to see how they are working things out
- Contact Chronic Care Consortium for help in figuring out billing once we go outside UIHC
- Get the word out; marketing, social media how to do this?
- Ensure all materials created are in English and Spanish
- How do we measure cost effectiveness of face-to-face vs tele-audiology?

**Discussion:**
- The group varied from very experienced programs (50-100 sessions) to states similar to Iowa who have only done a handful of diagnostic screens/sessions
- The UIHC umbrella has made information sharing much easier
- It may make it easier to catch up with long-term follow up
- The plan is to create a document for other states to use to help each other with lessons learned
- Q: How did the families that were served via tele-audiology respond?  
  A: Families are happy they do not have to drive to Iowa City
- Making this available statewide will be a challenge between the actual machines as well as training staff to do it
• There needs to be a balance for the parents—it may not be beneficial if they still have to travel and don’t receive face to face care

Guide By Your Side (Susan)
• Susan will be training or re-training guides at the Iowa symposium this fall
  o The current guides were hired before Susan, this will be a good way to figure out what’s missing
• They received their first self-referral from the website!

Refer Rate Data Analysis (Sylvia Petersen)
• Quarterly reports are sent to each birthing hospital (each quarter/every 3 months) so they can improve their miss or refer rates by following best practices and meeting state goals. IDPH has received phone calls from hospitals about these reports asking how they can improve their statistics. Some hospitals have made changes to improve rates, including staff training, updating their equipment etc.
• The refer rate analysis is an analysis of hospital refer rate percentages over the last three years. This allows IDPH to determine which hospitals have high refer rates, which ones are improving, and also to determine whether site visits and/or purchasing new equipment makes a difference.
• The follow up rate analysis was completed to determine hospitals that are getting babies rescreened, either at their own facility or referring them on to the appropriate provider. Information on whether or not the hospital rescreens babies themselves or refers them somewhere else will be added to these reports in the future

Family Resource Guide Work Groups (Vicki)

Activity was to separate into three groups to document observations of the current Iowa Family Resource Guide. Consider content, layout, look/feel, what is outdated, needs updating, and what is missing that could be added. Also consider the following: is it plain language, are there too many words, what about references to research, Do you like the stories intermingled with the info? What about the graphics; too busy, too grainy, outdated? How to handle information that can get outdated quickly (names, addresses, etc.)? Keeping in mind that this is a resource guide for families.

Link to Resource Guide:
http://www.idph.state.ia.us/iaehdi/common/pdf/iaehdi_family_resource_guide_english.pdf
  1. Intro activity 5-10
  2. 30 min small group
  3. 10-15 min report back to larger group highlights of discussion

NOTE: Please see attached document for notes on different sections of the resource guide.
Wrap up/sharing

**Iowa Symposium on Hearing Loss/National EHDI Conference** (Iowa EHDI Team)
- September 28-29, 2012
- Emphasis on the first day will be on delayed onset and progressive hearing loss
- Susan will be training guides for Guide By Your Side
- They need to know how many interpreters for the round table discussions
  
  *Suggestion: It might be helpful for the interpreters to have some sort of marker so the leaders/facilitators know who they are*

**EHDI Toolkit (Vicki)**
- Will be distributed at the end of summer
- Comment: Only sending the toolkit to PCPs who serve the most infants may be counterproductive; the providers seeing the other 15% may be the ones who really need the information
  - Doctors are still saying to wait a few months for rescreens; physicians are comfortable sharing results but not as comfortable with taking the next steps and making referrals, e.g. recently discovered a child who has been getting hearing screens for the past year rather than receiving a diagnostic evaluation

**Hearing Aid Funding**—Application, Funding announcement & the FAQs are in process.

**Case Management Module**
- New piece of the EHDI database (eScreener Plus™)
- EHDI and CHSC staff started using in April 2012, it will be expanded to audiologists around October 2012. It is a way to specifically record follow up activities: it will show contacts/attempts that have been made to primary care providers, families, birth facilities, etc. by email, phone, letter.

**Agenda Items for October**
- Wrap up on symposium
- Update on the Deaf Child Bill of Rights from Kathy
- Deaf Iowans Against Abuse (Jennifer Upah)
- Update on the EHDI Website and Logo

*Next EHDI Advisory Committee Meetings: October 11, 10-3 p.m. at Altoona Public Library*