Early Hearing Detection and Intervention Advisory Committee Meeting Minutes
Thursday, January 10, 2013
9 – 11:00am (ICN)

Members Present: Marcy Beisiegel-Clausen, Marsha Gunderson, Diana Hanson, Dr. Jeffrey Hoffman, John Cool, Leslie Huber, Linda True, Nick Salmon, Kathy Miller, Jill Simonson, Quentin Kennedy (student), Lindsey Crawford, Steve Sword, Bob Vizzini, Valorie Caputo, Emily Andrews, Jessica R. (Audiology Intern), Teresa Hobbs, Sara Lincoln, Mary Stevens.

Staff Present: CHSC: Leslie Huber, Susan Hagarty, Phyllis wood; IDPH: Tammy O’Hollearn, Esha Steffen

Introductions & Announcements
Members introduced themselves. No new announcements.

NAD Conference (Bob)
Before the NAD (National Association of the Deaf) conference, Bob went to National EHDI conference in St. Louis. Bob did not receive any funds to attend the conference; however, some of the Deaf community members willingly provided sponsorship for Bob to attend the meeting. There was good representation from the deaf community at the conference. CEO of the NAD, Howard Rosebaum, (originally from Chicago) was at the EHDI. Howard Rosenbaum, believes there is a lot of need to for the Deaf community to understand how to get involved in EHDI or work with parents of deaf children.

The NAD conference was held in Louisville. Bob noted it was a huge conference with about four times more display booths to EHDI's conference, and many people attended the workshops, and entertainments. Along with the five days of events, NAD held delegate meetings which Bob and Kathy Miller attended to represent Iowa. Bob stated that normally two delegates represent for each state. The business meetings took up a lot of time and were scheduled during other workshop times. The three EHDI related workshops all occurred during the delegate meetings. Bob said it was unfortunate that many state association leaders were delegates and had to miss out on the EHDI workshops. Bob skipped several delegate meetings to be present at the EHDI workshops.

He was a panelist at one workshop sharing his experience as a deaf advocate on Iowa's EHDI advisory. Bob shared with some deaf people that they should consider being a representative on their state EHDI advisory committee and consider being involved if their state EHDI program holds a conference. Beth Benedict, and a few other deaf leaders including actress Terrylene Theriot spoke about deaf infants and language development.

Bob shared the following comment about the feasibility Committee, “some people say early hearing detection helps and that, deaf children eventually obtain educational and equal access just as well as the hearing children but that is not true. A deaf child does not ever regain their hearing to communicate as well as the hearing children.”
Feasibility study updates (John)
The Feasibility and Planning Committee completed their study and have made recommendations to the Board of Regents. The recommendations include:

1. The Management Team for Vision Services and the Executive Team for Hearing Services be combined to create a Leadership Team for students who are Blind, Visually Impaired, Deaf, Hard of Hearing and Deaf/Blind.
2. Establish five Regional Centers including ISD and IBSSS as two of the regional centers.
   a. In partnership with LEA’s and AEA’s
   b. Regional Centers will add another option to the continuum of services for these students.
   c. ISD will continue to offer the residential option. ISD will be the only Regional Center to offer the residential option.
   d. Planning and implementation to begin upon approval by the Board of Regents.
3. There will be additional cost of approximately $3.2 Million.
   a. Leadership Team will work with partner agencies to develop agreements, analyze costs, and present proposed costs and proposed funding sources to the Board of Regents by September, 2013.
   b. Some costs will be shared through personnel assignment, contract for services, reassignment of personnel, reallocation of services and savings from centralized administration.
   c. Additional state appropriation will be necessary to implement this proposal.
4. Administration Services will be centralized.
   a. Administrative = Superintendent, Assistant Administrator, human resources, business functions, information technology and outreach.
   b. Program specific administrative functions = principal, program directors and regional directors will remain separate but under the direction of central administration.
   c. Examine potential advantages of cooperative services (payroll, accounts payable/receivable, etc.) with one of the universities.
5. Legislative approval, changes in Iowa Code and additional state appropriations will be necessary to implement these changes.
   a. The Leadership Team will submit information to the Board prior to Department of Management submitting recommendations to the Iowa Legislature.
   b. The Leadership Team and the Board Office will prepare necessary proposals for changes in Iowa Code and Administrative Rules.

Long-term follow up (LTF) update 2011/2012 (Leslie)

LTF monitors children who did not pass their second (outpatient) screen and need an audiology assessment. The LTF staff also follows children who pass their birth screen and have risk indicators for late-onset or progressive hearing loss.

Monitoring 321 babies (2011):
283 Received at least one Diagnostic Test
39 children NEVER had diagnostic testing
Leslie indicated that frequently, children must undergo more than one evaluation to get to a definitive hearing diagnosis (These children Remain “In Process” until a diagnosis is determined)
242 Completed Diagnostic Test Phase Results:
- 179 Normal Hearing
- 63 Permanent Hearing Loss
- 123 Remain In Process (Diagnosis: Transient conductive or Not Yet Determined)

DX by 3 months of age: 177 (63%) children (represents a 3% improvement from 2010; Goal is 100%)

Habilitation Information
50 Children were candidates for amplification
- 4 Parents chose not to use amplification
- 21 had the amplification fitting data in EHDI database, eSP™
  NOTE: Amplification information is not required by law

Early ACCESS/Early Intervention
- All children with hearing loss qualify for EA/EI
- National goal is that by 6 months of age infants diagnosed with a hearing loss are to be enrolled in EA
- Referral should be made by their medical home or audiology
- EHDI must note both referral date and enrollment date in EHDI database, eSP™
- Per eSP™: 35 children with permanent hearing loss were referred to Early ACCESS
- Per eSP™: 28 had the IFSP date documented in eSP™

Risk Factor Letters:
For babies born in 2011: 3,511 letters sent
For babies born in 2012: 2,656 letters sent
Intent: Remind caregivers of increased need for ongoing monitoring; stimulate discussion between parents and PCPs.

Comments from Parents:
- Alarm/fear; upset if needed assessment and were notified late; some reported being unaware of risk factors (i.e., child had a medicine that could affect hearing)

PCPs Comments:
- “Forgot” about the letter cycle; reported adding notes to scheduling tools they have in the electronic medical record

Areas for improvement noted:
A number of PCP’s sent the faxback form to LTF with no information (blank) or the original birth screen results
- 2011: 10% Faxback form sent back with no information (blank) or original birth screen results
- 2012: 15% Faxback form sent back with no information (blank) or birth screen results

Leslie stated that the OAE screener that was once at the Child Health Specialty regional clinic in Fort Dodge has been moved to UI’s loaner Bank. She stated that the screening was not being utilized and the hospital received AABR equipment therefore OAE screening is not an appropriate rescreen.
Cultural Competence Community of Learners Update (Susan)
Susan shared the cultural competence community of learners group consists of people from different states including Guam. It’s a great learning experience. We are currently putting together statistics on cultural diversity and determining factors that may play a role in lost-to-follow up numbers. The data has, so far, shown that socioeconomic status might be one of the factors but it does not appear that different racial/ethnic groups play a significant role in lost-to-follow up numbers. A detailed statistical analysis has not been done so it is hard to conclude the contributing factors.

Susan commented, “a lot of the guidelines are effective with all kinds of members; best practices are needed for all types of groups and not just culturally diverse groups.”

Guide By Your Side (Susan)
Susan noted that in 2010, there was no process or procedure in place for children that were diagnosed with hearing loss. The process depended on the referrals received from the audiologists, families and other professionals. In 2011, the LTF program contacted 37 of the 63 newly identified babies with hearing loss. Susan noted that the process is a little more challenging because some of the contact information including phone numbers for the families and primary care providers has changed since they were first reported at birth which makes it harder to track down the families and offer support.

Susan noted that in her experience, parent-to-parent contact has proved to be effective in bringing children that need a diagnostic assessment back in. She believes that parents feel more comfortable sharing their stories with a professional that is also a parent of a child with special needs.

EHDI website updates (Tammy)
The EHDI team at the Iowa Department of Public Health (IDPH) continues to work on re-designing the website based on the information gathered from committee members at the EHDI advisory committee meeting last year. Sylvia Petersen (EHDI intern) has helped design the website for us as our graphic designer as Heather Hobert is currently on medical leave until March.

Tammy displayed the recently designed home page and talked about how it may change slightly from page to page in areas such as the resource box. Tammy shared that with the new design, EHDI staff will be able to post content on the website much faster than it has been in the past because we will be trained to do it versus making a request to our information management staff and then waiting for them to post the changes. The new design will be reader friendly and will make it easier for the families to navigate. There will still be a parent’s page and professional’s page. Some of the content will be the same, but much of the content will be different. Tammy will provide another update at the next meeting.

Wrap Up/Sharing
Mercy Kudos
Tammy stated that she wanted to verbally share kudos directed at the efforts of Mercy Des Moines to improve screening follow up processes for infants born at their facility. She said that she has worked with Michelle Simmons at Mercy Des Moines for just over a year to change their procedures for follow up when an infant does not pass the initial birth screen. Tammy explained that they do not have an audiologist on staff and the ENT/audiology offices typically used do not have the equipment or a pediatric audiologist who can perform
diagnostic assessments for infants. Previously the hospital would refer the children to their local Area Education Agency which also does not have the equipment to perform a hearing re-screen for the children screened in the NICU with AABR that did not pass. Tammy reviewed the Joint Committee on Infant Hearing Screening recommendations with Mercy staff and let them know they could bill for outpatient hearings screens. After some consideration, Mercy decided it was a service they could provide for their families since there was not a provider besides Iowa Methodist that could screen with the same technology.

Tammy reported that Mercy has taken it a step further and also put protocols in place to refer immediately for diagnostic testing if a child does not pass their outpatient hearing screen to meet the national 1-3-6 guidelines and provide recommended follow up for that infant and their parents. Mercy must refer to Iowa Methodist since they are the only provider able to perform diagnostic assessments for infants or children under the age of six to seven months of age. Diana Hanson, pediatric audiologist, then refers to an ENT physician, as needed after she has determined that the infant does or does not have a hearing loss.

ENT/Audiology Survey: A survey will be sent out in about a month to audiologists and ENTs to determine their practices and referral procedures, etc. It will be available both electronically and also, in hard copy. The survey results will be available either at the April or July Advisory Committee meeting.

Suggestion: Marsha requested an acronym sheet for the ASL interpreters. Email the sheet to Marsha Gunderson at mgunderson@iowaschool forthedeaf.org

Agenda items for April
- Case management module demonstration
- Long-term follow up (2011 update)
- Home birth (update)
- Feasibility study (update)
- Tele-audiology
- Survey on Audiologist/ENT’s
- National Summit Meeting – at the end of Jan 2013 (update)
- Cultural Competence Community of Learners (update)

Meeting dates for 2013: April 4, July 11 and October 3