Early Hearing Detection and Intervention Advisory
Committee Minutes
Thursday, July 1, 2010
10:00-3:00 p.m.

Location: Lucas State Office Building, 321 E. 12th St., Des Moines, Room 201

Committee Members: Kathryn Baumann-Reese, Bob Vizzini, Marcy Clausen, Valorie Caputo, Reverend Dennis Konkel, Michelle Vaccaro, Grace Bargstadt, Steve Sword, Debra Waldron, Nick Salmon, Barb KHAL, Rebecca Young and Jane Borst

Staff: Tammy O’Hollearn, Peggy Swails, Vicki Hunting, Jen Thorud and Susan Hagarty

Introductions & Announcements

● New committee members. Tammy introduced new members to the EHDI Advisory Committee. Michelle Vacarro will represent parents of children who are hard of hearing and Grace Bargstadt will represent the AEA Special Education Directors. Tammy stated that Brenda Walker will replace Laura Malone as the representative for the Iowa Hospital Association. Brenda will attend the meeting in October.

● Iowa Health Job Opening. Tammy announced that Iowa Health is looking for a pediatric audiologist. The position is full-time; four days at Blank seeing children and one day at Penn Medical seeing adults.

● Overview of EHDI program. Tammy provided a brief overview of EHDI system for new members. Under Iowa legislation regarding Universal Newborn Hearing Screening, IDPH is designated as the entity responsible for collection of hearing screening and diagnostic information for children under the age of three. Hospitals are responsible for screening all newborns prior to hospital discharge. If a child is born within a birth center or at home, the primary care provider accepting responsibility for the child is responsible for assisting the family in scheduling a hearing screening within one month. Any audiologist (AEA audiologist or private audiologist), ENTs or healthcare providers who conduct hearing screens and/or assessments are responsible for reporting results to the IDPH.

Within the EHDI system in Iowa, there are two EHDI projects supported by federal grants: Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). The projects make up
the EHDI system in Iowa. Both projects work together to build a seamless system of care for children. The CDC project is administered by the Iowa Department of Public Health (IDPH) and the HRSA project is administered by Child Health Specialty Clinics (CHSC). IDPH EHDI focuses on newborn hearing screening, surveillance through diagnosis and enrollment in early intervention and program evaluation. CHSC EHDI focuses on follow up (including re-screens, diagnosis and referrals to early intervention) for children who are deaf or hard of hearing and family support.

Tammy provided an example of how far the program has come since 2004. Tammy offered to share a copy of a Power Point presentation that she and Erin Kongshaug, previous EHDI Follow up Coordinator did to talk about the work of the programs and the infrastructure building that has taken place since 2004.

- **eSP Enhancements:** The EHDI program received enhancements to the assessment section of the EHDI data base. The old version was very cumbersome and time consuming for audiologists. A number of private providers are currently sending in paper forms. Now that the system has been updated and is user friendly, IDPH EHDI will work to bring private providers online to report their results through the web based system. Tammy offered to provide a demonstration of the EHDI data base for anyone interested. The EHDI program has a user manual available on the EHDI website, [www.idph.state.ia.us/iaehdi/common/pdf/escreener_plus_manual.pdf](http://www.idph.state.ia.us/iaehdi/common/pdf/escreener_plus_manual.pdf). Tammy noted that audiologists interested in instructions for entering data into eSP can contact her. Tammy shared that she has been contacted by a few audiologists since the upgrade over the weekend about the new audiological assessment piece of eSP and the comments have been very positive. Everyone reports that the assessment section is easy to use and has decreased data entry time.

- **HRSA and CDC grants (Peggy)**

  Peggy reported to committee members that new grant guidance will be coming out from CDC and HRSA for the new three year grant cycles. The shared goals for both programs are based on national goals referred to as 1-3-6: screened by 1 month, diagnosed by 3 months, and enrolled in Early ACCESS by 6 months. Tammy reported that they anticipate that the federal programs will continue to fund the same types of activities for each grant continuing the work of previous years. Both grant applications will be competitive. The HRSA grant runs from April until March 30th each year and the anticipated release date for the guidance is in the fall. The CDC grant runs from July through June 30th of
each year and the anticipated release date for that guidance is February or March 2011.

- **ABBR placement (Peggy)**
  St. Luke’s in Sioux City was selected as the location in NW Iowa where AABR equipment was needed. St. Luke’s was picked for several reasons; 1) they birth a large number of children, 2) they have a high refer rate (much higher than what the state has set as a goal for hospital programs), 3) they have a NICU and AABR screening is the recommended (by Joint Committee on Infant Hearing Screening-JCIH) piece of screening equipment to be used on children in the NICU. AAEAs can only screen using OAE equipment and 4) families must travel a long way to have their children screened by recommended AABR equipment.

  On a positive note, St. Luke’s has decreased their refer rate considerably since a technical assistance visit by Nick and a site visit last summer by Tammy and Nick. The nurses indicated that they have made a concerted effort to place greater importance on the hearing screening process which has lead to a decrease to 6% which is the state goal for a refer rate.

  St. Luke’s will receive the machine and training within the next month once the contract is signed which outlines their responsibility and EHDI program responsibilities. The contract will require that St. Luke’s re-screen children birthed at their facility, as well as children born at another location who may be in need of an AABR screen. It will require the EHDI program at St. Luke’s to come into compliance with the refer and miss rates required by the state program. The piece of equipment and additional training should assist St. Luke’s in meeting this requirement. The program will also be responsible for reporting and covering the costs associated with yearly maintenance and calibration and disposables required to screen children.

  Peggy reported that they will also be purchasing another AABR machine that will be used to pilot tele-health in areas where a diagnostic provider is of great distance for parents. Lenore and Emily will assist CHSC’s EHDI in piloting this project. The pilot area has not yet been determined. In addition, Peggy said that they will also purchase two pieces of OAE equipment to be used in the state for hearing rescreens.

  Tammy reported that Ottumwa AEA is in the process of purchasing a new piece of diagnostic equipment that they will use to provide unsedated ABR’s for children in their area. Tammy noted that it will be extremely important for
hospitals to refer the children right away if a child does not pass a hearing rescreen. In addition, the AEA will assist Ottumwa Regional Health Center in completing AABR screens for children who came out of their NICU until they purchase their own equipment.

Tammy shared that Lenore applied for a grant to test the new AABR technology being sold to see if the equipment is able to gather accurate diagnostic assessment results for children who are not sedated and who may not be totally still. Tammy shared that she and Emily saw this equipment and heard a presentation at the National EHDI conference and Lenore and Diana Hanson also had presentations by the vendor. The equipment shows some promise as being able to obtain test results while a child plays or is in a stroller, etc. She also noted that there is a push at the national level to get away from sedating children due to risks associated with sedation and the need for timely diagnosis.

- **Additional Announcements:** The hearing loss symposium will be held Sept. 17-18th, 2010 at the Courtyard by Marriott in Ankeny, Iowa. Tammy sent out this information in an e-mail to all EHDI Advisory Committee members asking that it be disseminated to constituents and parents of children who are deaf or hard of hearing. CEUs will be offered. The EHDI program is also trying to increase the number of parents who attend. Scholarships are available to parents, as needed and one nurse from each birthing facility is being offered free registration for their EHDI contact to attend. For those parents interested in a scholarship, they should contact Vicki Hunting, Susan Hagarty or their local AEA Parent Educator Connection designee. Tammy reported that EHDI personnel will be doing a training update that morning for audiologists that use the database or those interested in using the database. Vicki reported that a Guide by Your Side (GBYS) training will be on Saturday afternoon for guides. GBYS is funded through the HRSA grant. Tammy noted that the brochure is available on the Iowa EHDI website, [http://www.idph.state.ia.us/iaehdi/default.asp](http://www.idph.state.ia.us/iaehdi/default.asp) at the top of the parents or professionals web page.

- Deb Waldron shared that she is has been selected to serve on the National American Academy of Pediatrics EHDI Task Force.

**Guide by Your Side (Susan)**

Susan reported that she attended an EA Regional Liaison meeting most recently to share information about the GBYS program and how to make referrals. She plans to visit other AEA’s to talk about the program and reinforce that the program is
available to parents of children who are deaf or hard of hearing for support. Val suggested that Susan also include itinerant teachers when she goes to the AEAs. Susan also plans to meet with audiologists at diagnostic centers across the state.

Susan is no longer assigning guides based on geography. She is working on matching up families with guides who have been in similar situations. She recently surveyed all guides to gather more information on their experience, etc. Susan reported that she is in the process of developing a tracking system for referrals. Previously there was no consistent tracking system in place for inquiries, referrals, follow up, enrollment, guide assignments, etc. She plans to increase training for guides and stay in touch with them on a regular basis.

Referrals for the last few years:
2008 – 3
2009 – 4 to 6
2010 – 4 as of July 1

Susan reported that more referrals are coming in each day! Referral forms have been updated and are on the Iowa EHDI website, [http://www.idph.state.ia.us/iaehdi/default.asp](http://www.idph.state.ia.us/iaehdi/default.asp). GBYS has its own page on the EHDI website with information about the program, who it serves, etc. Tammy reported that she had talked to a couple of parents on the phone about other resources and inquired if they would be interested in a referral to GBYS. They agreed and a referral was made. Tammy said she believes it will take off if professionals bring it up.

Finally, Susan shared the new GYBS brochure. It is a one page insert that easily fits into the Iowa Hands & Voices brochure. If you are interested in more brochures, contact Susan.

Vicki spoke about two new videos available on the Iowa Hands & Voices website, [www.handsandvoices.org](http://www.handsandvoices.org) website: *Lost and Found* and *The Time is Now*. The *Lost and Found* video has families of children identified through newborn hearing screening speak about the importance of newborn hearing screening and follow up. The *Time is Now* video is about the importance of linking to the deaf and hard of hearing community! Both videos will be shared with the advisory committee in October when wireless internet is available.

**EHDI Program Indicators/Data (Jen/Tammy)**

Jen presented updated 2009 EHDI data. Jen indicated that our data is similar to that in 2008. She noted that our data may change slightly as we are still doing some
additional follow up on 2009 babies still “in process.” Jen noted that refusal rates have increased in the past few years; however, Tammy noted that the increase in refusals is more likely due to better reporting than an actual increase in refusals. Overall, few of our babies are marked as “lost contact”; however, of these, more are lost between outpatient screen and diagnostic evaluation.

Jen pointed out that many of the home births result in a refusal or never receive a screen and are later marked as “lost contact.” Tammy reviewed the process that the EHDI program follows for getting information to families who birth their children outside of a hospital. She also discussed that she has met with the vital records program and asked that some additional data be gathered when they look to update the birth worksheet that may assist the program with additional follow up. It was suggested that we might think about providing scholarships for midwives to attend the symposium in the future.

Jen reported that we are doing well at providing babies with the initial hearing screen and our numbers of have increased in 2009 for getting children back in for a rescreen for children who do not pass their initial screen or are missed. We are also doing well as a state at ensuring NICU babies are screened and of those NICU babies receiving an outpatient screen, a majority of them pass.

The following is a list of additional data pieces that members of the Advisory Committee would like presented at future meetings:

- Normal hearing with and without risk factors
- Breakdown by race/ethnicity
- Refused number of children with risk factors
- Data match with metabolic screen refusals compared to hearing screen refusals
- Amish—have the screening programs impacted the number of children in these communities being screened
- Brief overview of CDC report comparing state results
- Include a slide with the newborn hearing screening and follow up goals from: Healthy People 2020, HRSA, and CDC.
- Break out children in NICU vs. Well-baby
- Include HRSA/CDC target goals on performance indicators
- How many providers improved their refer or miss rates, reporting, etc. since their site visit? How many providers are now providing OP hearing screens that weren’t previously?

*Include raw numbers on slides

**NICHQ (Vicki)**
Vicki presented data to summarize the outcomes related to the NICHQ project. She provided examples of the small tests of changes that were successful throughout Iowa. She also talked about efforts to spread these tests of change throughout the state in birthing facilities and AEAs.

**Hearing Aids and Audiological Services (Tammy)**

Steve Sword talked about the new technology available for children who are hard of hearing. He brought examples of a hearing aid and a piece of an FM system that children use with their hearing aids for amplification. Steve commented that the size of the hearing aids has decreased over time and wireless technology is increasing.

Tammy provided a brief update on the Hearing Aids and Audiological Services funding made available through a small appropriation by the legislature. An article will be included in the fall newsletter, including a list of the biggest providers for the program.

Tammy shared that the amount appropriated each year has slightly decreased. Last year the funds were available from July 1 until mid October when they were put on hold due to an executive order by the governor to cut spending to assist with the budget crisis. Those families who had submitted an application that was in process were placed on a waiting list and no additional applications were accepted due to the uncertainty of the funding. Tammy reported that the funding was eventually restored at the end of April. Those families who were on the wait list were contacted to determine if they still needed the funding. The challenge for the program, parents and providers is that the children needed to be served by the first part of June. There were a few families and providers that could not meet that deadline. Fortunately, the legislature approved a small appropriation for 2010-2011. Those children who were not served in June were bumped to July.

Tammy stated that she would put together an article in the fall newsletter summarizing the children served, funding used, etc. Preliminary data indicates that 134 kids enrolled into the program and 124 of those children had at least one paid claim. The average number of claims per child was 1.26. The average dollars spent per child was $1200. Following is a breakdown by age of children served:

- 0-3: 19%
- 4-10: 45% (these kids most likely had hearing aids at young age and needed upgrades)
- 11-15: 20%
- 16-20: 16%
One of the committee members asked if Medicaid families are included in the numbers. Tammy explained that children eligible for Medicaid or hawk-i are not eligible for this program. If the family has private insurance, they must have proof that their plan does not cover the cost of hearing aids or audiological services they are applying for with the Hearing Aids and Audiological Services program. Children eligible for Medicaid or hawk-i are covered under those programs for hearing aids and audiological services. Tammy reviewed the percentage of families with insurance whose plans did not cover hearing aids and/or audiological services. Blue Cross Blue Shield amounted to 62% while United Healthcare, Principal and Coventry were 11% or less.

Most kids served were in need of hearing aids. Typically assessments are covered by insurers so it is rare to receive a claim for assessments. FM systems are available through this program only if there is a documented need for the system at home due to safety or development. Tammy explained that a number of children have these systems available to them within the schools, but they cannot take them home. Tammy shared information from a letter she received from a parent about a child who received an FM system at home and the difference it has made in the life of their child.

This year the appropriation is for $190,028. The funding was available July 1 and will be available through June 30th, 2011 or until funding runs out or a freeze is placed on the funding this year. An updated application and frequently asked questions sheet has been posted to website. All audiologists in the AEAs and private practice who have worked with the program were notified of the funding opportunity. Tammy noted that a number of applications have already been received. Top ten providers that worked with the Hearing Aids and Audiological Services program will also be included.

One member noted that John Deere has a hearing aid benefit. They recently were bought by United Healthcare. Steve noted that there are a number of trust funds and other resources also available, but you have to dig. He also said that some hearing aid companies have kids clubs for children in need of hearing aids. He stated that they are usually generous with the type of aid provided. It was noted that some AEA audiologists are very resourceful at finding other funding. Steve indicated that his association may work with the Lions Club of Iowa to set up some sort of resource for families of children in need of hearing aids. He will keep the Advisory Committee informed if anything develops. Tammy noted that a list of other funding resources is on the website. She said that 13 states have been successful in getting legislation passed which mandated hearing aid coverage for kids. She also said that there is an effort at the national level to address this issue.
Program Evaluation (Jen/Tammy)
Jen provided the committee with handouts that included the EHDI program evaluation logic model, program indicators, possible evaluation questions and a handout to prioritize the focus areas. Jen provided an overview of the progress of the steering committee that is made up of a few of the EHDI Advisory Committee members, as well as EHDI program staff. She talked about the work of the group thus far in developing the logic model, revising the program indicators as a tool to be used for program evaluation, gathering preliminary evaluation questions and so forth. Jen indicated that she will create a timeline for evaluating the various components of the EHDI system once the different components of the system to be evaluated are prioritized.

Jen asked EHDI Advisory Committee members to prioritize EHDI system components to help the program narrow the focus areas that will be concentrated on in the upcoming year. Jen will provide ongoing updates regarding program evaluation in October.

Wrap up
- Agenda items for October
  - Additional data items
  - Follow up and highlights from symposium

Next EHDI Advisory Committee Meeting
- October 7, 2010 – Altoona Public Library
  - 10-3 p.m.