Early Hearing Detection and Intervention Advisory Committee Minutes

Thursday, January 6, 2011
9:00-12 Noon

ICN Locations: Lucas State Office Building, 6th Floor-Des Moines, Muscatine Community College, Iowa Central Community College-Fort Dodge, DMACC-Ankeny, Creston AEA, School for the Deaf-Council Bluffs, Guttenberg-Clayton RDG HS, Mason City High School

Committee members: Marcy Clausen, Lucinda Hollingshead, Lenore Holte, Barb Khal, Valerie Lynch, Suzy Mannella, Don Miksell, Sally Nadolsky and Brenda Walker

Staff: Emily Andrews, Vicki Hunting, Tammy O’Hollelearn, Nick Salmon, Peggy Swails and Jen Thorud

Introductions & Announcements

- Don reported that they have started an e-newsletter. You can sign up by sending a message to IADE-NEWS@q.com or contacting Don at dmiksell@q.com. Tammy reported that President Obama signed into law the Early Hearing Detection and Intervention (EHDI) Act on December 22, 2010. The legislation supports the development of efficient models to ensure that newborns who are identified with hearing loss through screening receive follow-up by qualified health care providers. It also requires the secretary of health and human services to assist in recruitment, retention, and training of healthcare providers.

- Tammy reported that the hearing aids and audiological services program funds are obligated at this time. Any applications that were already being processed will still be processed. New applicants will be notified there is no funding available for the remainder of the year. Tammy will include this information in an email to advisory committee members to share with constituents.

- Valorie brought up a question from Dr. Young regarding the process for testing babies who did not pass their birth hearing screen for CMV. CMV is an acronym for Cytomegalovirus, a risk factor for hearing loss when mom contracts it during pregnancy. Tammy indicated that an email was sent to Dr. Young recommending he speak to Kim Piper, State Genetics Coordinator following the meeting last October.

Lenore shared that the EHDI program and metabolic screening program under the direction of Dr. Sara Copeland explored CMV testing, however, there were a
number of challenges with this testing. Lenore’s short answer to this question is that the blood spot screening is not sensitive enough to pick up non symptomatic children. It is this group of children who we are most concerned with since they do not show symptoms. The group looked at other specimens (such as urine, etc.) but that would change how the screen was taken in the nursery.

- Lenore alerted committee members about an issue that came up recently related to diagnostic ABRs in the Waterloo area. Some young children in the Waterloo area failed a newborn screen and went on for a diagnostic ABR that were reported to be normal. The children later went to UIHC’s Otolaryngology department and were diagnosed with a mild to moderate hearing loss. Upon review of the ABRs, none of the children had normal ABRs. Emily and Lenore were contacted to see what needed to be done so that this did not happen anymore. Tammy and Lenore had actually tried to contact the audiologist about a similar issue, but she did not return their calls. Tammy spoke with the licensure board and Lenore talked with a board member. Barb Gienapp with UIHC Otolaryngology has since written a letter to the audiologist offering to talk to her about the discrepancies and provide additional training on how to do ABRs and how to read the results in hopes that the audiologist will take advantage of the training and avoid further mistakes.

Lenore stated that the committee needs to be aware that accurate diagnostics is an important piece of follow up. We need to be keeping an eye on what is going on in diagnostic centers in Iowa. We would love a resolution where training is provided. We are hoping to find a positive solution for everyone. Having one less diagnostic center is bad, but if they are not providing accurate diagnoses, that is a bigger problem. If you have questions, please contact Lenore, Emily or Tammy. Lenore reported that this is alarming, but it happens in other states, as well. Lenore shared that it happened in another state where Tammy was contacted by a hospital. The same kinds of errors were happening that involved quite a few cases. Lenore ended up working as a consultant with the other hospital.

Tammy was also contacted by another group regarding a child who was being evaluated by an AEA in preschool with developmental concerns. After Tammy looked at that child’s record in eSP, it showed a data entry error was made. The child’s record showed they did not pass their birth screen or outpatient screen. The audiologist recommended that they be seen by an ENT. However the result entered for their outpatient screen was a pass in both ears. The family did not follow up with the ENT and recently was diagnosed with a loss. Because of the error, the record was not flagged for additional follow up. In this situation, the
ultimate responsibility lies with the family because they never followed through with the recommendations of the AEA audiologist. However, data entry errors continue to be a concern. Quality assurance is extremely important for all providers and is being stressed during hospital site visits and contact with AEAs and private providers.

**Jill Glidewell, CDC presentation- Evaluation of the Iowa Early Hearing Detection and Intervention Data System**

Jill is a new EIS officer at CDC who helped with the EHDI program’s data system evaluation and development of a parent survey that will mailed out in the spring to approximately 3000 families, including homebirth families.

The Epidemic Intelligence Service (EIS) program at CDC is a two year training program in applied epidemiology. Jill is a nurse by training. Most recently, she was a consultant to Georgia newborn screening program. Prior to that, she was a pediatric nurse in the NICU before receiving her MPH degree. There are a number of objectives for an EIS officer. One of the first objectives is to complete a surveillance system evaluation. This presentation was given to her fellow EIS officers and other surveillance ‘gurus’ at CDC. Jill noted that the beginning of the presentation will be very familiar to the advisory committee, but it was not familiar to the original group.

**Summary of Jill’s presentation**

Congenital hearing loss affects 2 to 3 infants per 1,000 live births. If left undiagnosed, it could result in learning difficulties, language delays and behavior problems. Considering half of children have no identifiable risk factors, it is recommended to have universal screening program for all newborns.

National goals are to have all babies screened by 1 month of age, diagnosed by 3 months of age, and enrolled in early intervention by 6 months of age. Iowa’s EHDI program contracts with an external vendor for their web based surveillance system which tracks screens, rescens and diagnostic assessments. There is a two stage authentication process to login into the system. Features of the system include comprehensive hearing screening and assessment data, identification and tracking of children with hearing loss, ability to run quality assurance reports including a birth admission screening, follow up screening, and aging reports, notifications and letters, appointment scheduling, and identification of clusters of hearing loss. Jill’s evaluation was based on the published Morbidity and Mortality Weekly Report (MMWR) surveillance system guidelines as well as through staff interviews and electronic survey to users.
The surveillance survey results show that 51% of respondents were nurses and 70% were from birthing hospitals. Most data entry of demographics and screening results is through manual entry. Twenty-three percent of hospital users were asked if they compared their monthly census with the number of kids entered into the data system. Thirty-four percent of hospital users use the birth admission screening and follow up screening reports to track miss and refer rates.

Iowa’s data system follows most of the guidelines outlined in the MMWR report. Jill reported that Iowa does a good job in capturing screening data on every birth, the system is easy to use for a majority of the users, a large percentage of respondents reported weekly data reporting in line with the six day reporting requirement. Currently Iowa is unable to report on sensitivity due to the difficulty in calculating false negatives as well as the positive predictive value since we have children who are lost to follow up/documentation.

Recommendations include training users on the system’s existing capabilities, continuing to minimize infants lost to follow up, create a plan to look at false negatives, conduct a cost benefit analysis, obtain long term funding and continue efforts to integrate EHDI with other child health data systems. Important lessons learned from the evaluation include: the integral, but challenging relationship with information management and vendor, data quality is influenced by multiple factors, sustainability is vital, coordination and collaboration, financial resources, policy support, and ongoing evaluation is necessary for the improvement of the Iowa EHDI program.

Questions/Comments:
One of Jill’s recommendations related to false negatives. Lenore commented that it is very difficult to figure out this number due to late onset hearing loss, so we will not have 100% accuracy. Jill reported that this concern is completely understood. Jill reported that in the six months she has been with CDC, many of the evaluation guidelines are based around infectious disease surveillance which is completely different than programs such as EHDI.

Lucinda commented that nurses try their best to meet the six days requirement for reporting, however, if the baby is on oxygen that is more important than getting the hearing screen done in six days. Tammy explained that Iowa law and rules allow the exclusion for NICU babies who need to be stabilized before being screened. Jill clarified that the reference in this presentation was to the number of well babies who do not get their results entered within the six day timeframe.
A question was asked when the advisory committee could expect to get updated screening numbers for 2010. Tammy reported that a preliminary report will be made available in April at the next meeting. Tammy reported that as of today, January 7th, not all babies born at the end of December will have their results entered into the system yet. By April, the data should be more completed and more follow up completed on those children in need of a re-screen or diagnostic assessment.

A question was asked about the compatibility with electronic medical records (EMRs). Are EMRs too much in their infancy to discuss that related to EHDI? Jill explained that is one factor, but it was beyond the scope of this evaluation. Tammy followed up that the numbers of hospitals who are importing their demographics from EMRs are increasing because more hospitals are moving to EMRs while others wanted to get the data entry process under control before beginning the import process. Tammy explained that some of the largest hospitals import demographics and others also import hearing screen results. In Iowa, the e-health group is working on this issue; however, their focus is currently on connecting immunization and infectious disease surveillance programs with vital records and hospital electronic medical health records statewide. Tammy reported that there are also internal discussions within IDPH to integrate child health systems. Tammy reported that she has been advocating for integration since she arrived in February 2006. She said that it has been a very slow process, but each year they get farther in the discussion and development talk.

Tammy has been involved nationally with the CDC EHDI program, OZ Systems and various vendors on the process of moving information from the birth record to the surveillance system and out to clinic records so primary care providers have access to needed results and recommended follow up. John Eichwald, CDC EHDI Team Lead and Terese Finitzo, CEO of OZ are working with a group of individuals including vendors for electronic health records, hearing screening equipment and others to put together a case module that will demonstrate interoperability for newborn hearing screening. The group plans to provide this demonstration later this month at the Connectathon and HIMMS showcase in Orlando, Florida in February. The demonstration will include the transfer of EHDI data from the EHR and hearing equipment to the hearing surveillance system to vital records and back to the hospital/clinic to provide primary care providers with the results and recommended follow up. Tammy feels fortunate to be a part of these discussions as she continues to advocate for integrated systems within the department. When Tammy trained hospitals in 2006 and 2007, they were trained on how to import demographics, but many chose not to do it at that time because they were in the process of getting electronic health records, etc. As the program moves forward, the EHDI program will
strongly encourage providers to move in this direction. It cuts down on data entry errors and saves the provider’s time.

Don Miksell asked a question during this discussion if screening within six days was enough time. Tammy explained that the screen is usually done around 24 hours of age or sometimes sooner. Tammy said that babies are also screened later if they are ill and in the NICU. Birth certificate reporting has the same set of guidelines. Lucinda reported that some hospitals have developed a checklist to ensure screens are performed within 24 hours. Another committee member asked if there are any penalties for not reporting on time. Tammy said that the IDPH would work with the facility to make changes in how their processes rather implement penalties. She said that we try to work in partnership rather with birthing facilities as it results in better outcomes for children, families, hospitals and the program. Tammy said that if they weren’t successful in their work with the EHDI contact, they would contact hospital administration and if not successful, we would involve the IDPH Assistant Attorney General.

Jill welcomes any additional questions; feel free to email her at jill.glidewell@cdc.hhs.gov

**Hearing Screening/Diagnostic Equipment update (Peggy)**

Peggy explained that a memorandum of understanding (MOU) was signed between St. Luke’s - Sioux City and CHSCs EHDI in August for the placement of AABR equipment in their hospital. The equipment is to be used to screen NICU babies, babies in the well baby nursery that did not pass their initial screen and to re-screen all NICU babies at that do not pass their initial hearing screens at an outpatient screen.

**St. Luke’s contract – AABR unit (Nick)**

Nick provided background information about St. Luke’s. St. Luke’s is a large hospital (Level II) in Sioux City. St. Luke’s was chosen for a number of reasons including their high refer rate (in excess of 20% in 2008), NICU with no AABR equipment and the lack of an AABR unit in that geographic area to be able to provide outpatient screens to the community as a whole. Nick trained 22 NICU staff on the MOU and the AABR unit on Sept 20 - 21, 2010. Since then, he has had a couple of meetings with them, the last on Dec 2nd 2010. Nick looked at 4th quarter 2010 data this morning, the refer rate was less than 2% showing great progress and all kids in NICU were screened. Tammy and Nick noted that the details for outpatient screens for kids that do not pass their initial hearing screens are still being worked out.

Lenore mentioned that prior to the AABR unit being placed at St. Luke’s, if kids referred their birth screen, they had to go to South Dakota or Boys Town so many
kids were not getting follow up appointments. Tammy thanked Nick for his work. Tammy commented that they had a site visit a year ago this summer which was not the most positive. The hospital was struggling with leadership and organization. She noted that the change in leadership has helped a lot as well as the commitment of the CHSC EHDI staff to place the equipment in that area of the state. Nick commented that several Northwest Area Education Agency (AEA) staff attended the meeting on Dec 2nd and discussed how they could collaborate.

**OAE screeners**
Peggy reported that HRSA EHDI funds were used to place purchase two additional pieces of hearing screening equipment (OAEs) to be used in the CHSC regional centers. Peggy reported that the centers were chosen to give families another place to go for an outpatient hearing screen beyond the AEAs. EHDI staff will train nursing staff in Fort Dodge and Oelwein in January. If the pilot goes well, the HRSA EHDI program will purchase two devices per year over the next three years to place in the other regional centers.

The HRSA EHDI program also purchased two new OAEs for the loaner bank. They will then have seven pieces of equipment that is available to be loaned to hospitals when their equipment is broken and being fixed or they are having their equipment recalibrated (recommended once per year). There will be no loaner bank after the equipment breaks or expires (equipment parts are no longer available). Lenore and Nick commented that the program has been a huge help for hospitals. It helps them avoid missing children’s hearing screens which can then lead to children becoming “lost” if they are not successful in getting the family back.

**Telehealth (Lenore)**
Peggy reported that they also purchased ABR diagnostic equipment for telehealth with money from Early ACCESS ARRA stimulus funding. Lenore and Emily will determine where to place it but wanted to test it out at the Center for Disabilities and Development (CDD) before putting it out in the state. Emily and Lenore have been able to use it on one patient and a few other people. Overall, it has worked well, but they have also had a few issues too. Emily reported that it worked great with a seven month old baby with Downs syndrome. Emily was able to get normal thresholds. However, Emily brought in her baby but they couldn’t get the equipment to work. They called the company and were not happy with the service call. Emily and Lenore report that they want to make sure they get reliable data with the Bluetooth technology and averaging before they place it in another part of the state. Both Emily and Lenore are optimistic. Peggy commented that they plan to do diagnostic ABR through the regional clinics with Lenore or Emily based in Iowa City.
Lenore and Emily will be going to Marshfield clinic in Wisconsin in March to talk with them about teleaudiology. There are also audiologists in North Dakota who have had success with different equipment. Originally, they talked about working with AEA audiologists, however, due to liability and reimbursement issues, they have decided to use the equipment in the CHSC regional clinics.

**HRSA Grant Submission (Peggy)**

Peggy spoke briefly about the goals outlined in their recent grant submission. One of strategies in the new grant application is to create a medical home implementation team. They want to increase the educational campaign in collaboration with Dr. Sullivan and Dr. Larew, a staff physician with CHSC.

Barb stated that there have been several meetings over the last six months with the EHDI team (CHSCs and IDPH EHDI staff) to look at roles and responsibilities, as well as outline who will pay for various activities, data base, outreach and personnel. One change is that CHSC will complete long term follow up (follow up for children who did not pass their second screen and children with risk factors) and contract with IDPH to complete short term follow up (children who were missed or referred on their birth screen and require an outpatient hearing screen).

**Hospital Quarterly Reports (Tammy)**

Last year, a workgroup was assembled that included Tammy, Jen, Nick, Emily, and nurse representation from all hospital levels. Jen prepared a draft report and sent out to the group for feedback. A conference call was scheduled which gave hospital representatives the opportunity to provide feedback. Slight changes were made to the report. Following the call, a copy of the report for their hospital was e-mailed for additional feedback. All hospital personnel responded that they were pleased with the way the reports looked and thought they would be useful.

An updated draft of the report is included with the minutes. The first part of the report shows the birth admission screening report which hospitals can run themselves fairly easily. The report lists the data by month as well as by quarter. The next section includes the follow up report which can also be run in the data system, as well. The follow up report includes information on those kids that need follow up (either a missed or referred birth screen), if they got back in. For hospitals doing their own follow up, it tells them how well they are doing at getting kids back in for rescreens. If the hospital is making referrals to their local AEA, it tells them how successful the AEAs are at getting the kids back in for the outpatient re-screens. The report also includes a portion of the aging reports which are also run from the system. If the refer rate is high, this report can show if your screeners are screening too soon. It will also show how long it is taking the hospital or AEA to get the kids...
back in. You can break it down by days or months. The report highlights the miss and refer rates from the birth admission screening report. This shows the facility rate, average rate for other hospitals of the same size and and the state goal (there was an error in the draft, it should say goal, not average). The next section highlights the loss to follow up/documentation rate, number of kids with no PCP listed in eSP, and the number of days to enter demographics into eSP with both the average and range. One thing to remember if there is no PCP listed, they could have been removed if we found they were the wrong PCP during follow up or it was never entered or there is a case note with the PCP listed because they see someone out of state. The next section shows the number of kids that were not entered into eSP). Every few weeks, IDPH completes a data match with vital records to ensure all kids are entered into eSP. If there are kiddos who we cannot find in the system, we contact the hospitals to enter them. We have tracked this for the state since 2008; however, we only recently started to track it by hospital. That is why there are no numbers before August. Finally, contact information for Nick, Emily and the loaner bank is included for hospital’s reference.

Tammy noted that there will be one additional item added to the report, child outcomes which include the number of kids lost, diagnosed with hearing loss, and the number diagnosed with normal hearing. We feel as this is important information to give back to the nurses to show how their work at the front end makes a difference in the outcomes of children they serve. Currently, they do not know the outcomes of the kiddos they screen.

Tammy reported that there will be guidance on how to read the reports as well as how to run the birth admission screening, follow up screening, and aging reports within eSP. These reports will go out quarterly starting in April with quarter 1 of 2011. The purpose of these reports is not to focus on the negative. We want to give feedback to hospitals more often than yearly or every 2 years through hospital site visits. We want to reinforce what they are doing well and show them areas that they need to make improvements. The original plan is to send these to the EHDI contacts at each hospital. If we continue to have issues, the reports will go to hospital administration. We have no intention of publishing these reports as other states do at this time. As we have said, we want to work in partnership with the hospitals. There are circumstances that could change these numbers at any time (weather, change in personnel, change in leadership, equipment breaks, etc).

Barb stated that she liked the reports. She suggested we include the percentage with the number of kids with no PCP listed in eSP as well as the number with the percentage of kids missing in eSP. The percentages will be included throughout the report where available to help give the readers a perspective of what the numbers
mean. A concern was brought up about the PCPs. Valorie noted that by the time they see kids they may not have a PCP listed or it is different or they go to a clinic, but may see more whoever is available and it may differ from who is listed in eSP. Tammy explained there are many scenarios. Sometimes a family may plan to go to a doctor; they go the first time and then go to someone else later because of a personality conflict or need. Tammy reports they do the best they can to track down the new PCP by speaking with families or checking one of the child health databases. She stressed that it is important for hospital personnel to verbally inquire rather than assume the physician seeing the child in the hospital is who they will see because it may or may not be the case.

**Hospital Site Visits (Tammy)**

Tammy reported that approximately forty-four hospital site visits have been completed and a few more are scheduled including training at a regional CHSCs center in Fort Dodge. We are also finalizing hospital site visits in the Oelwein area and training at the CHSCs regional center. We try to group site visits together for hospitals in the same area of the state, usually two or three per day.

Tammy explained that there is a lot of preparation and follow up after a visit. Each hospital is asked to complete a self-rating rubric. The rubric includes protocols, best practices and requirements to meet Iowa law or rules related to newborn hearing screening and follow up. To the visit, Tammy brings copies of the birth admission screening and follow up screening reports. Nick and Emily view their equipment, screening location and inquire about their screening processes. Upon review of the data they discuss what issues they may have that contribute to a higher miss or refer rate and try to troubleshoot the issue. They review the rubric and processes, how they gather information from families, assist with follow up, screen, communication with parents and the primary care provider, etc. Following the visit, Tammy puts together a report that identifies strengths, areas for improvement and strategies/resources for improvement. It first gets sent to EHDI staff that attended the visit to add/edit the report. It is then sent to the EHDI contacts at the hospitals in draft format. This gives the EHDI contact an opportunity to ensure we did not misinterpret their processes. Once they review the report, Tammy sends the final report to the EHDI contact and hospital administration (quality assurance coordinator, chief nursing officer, VP of nursing, or other individual).

Tammy, Nick and Emily reported that they believe the visits have been very successful. In April or July Tammy said that they will provide additional data on the visits and whether they have resulted in changed practices, etc. When possible, the team plays a DVD of a message from a parent whose child was diagnosed with a
hearing loss. The team has heard from a few hospitals that they would like to have a copy of the DVD to show families during their stay.

Emily felt that hospitals appreciate the EHDI staff being able to talk with them and help them troubleshoot. The hospitals appreciate the positive feedback, as well. Tammy stated there are things you can’t measure in the data system or through surveys, but talking in person really helps the program to know what the challenges are in the field, who is doing well and who needs additional assistance. The team has also suggested that hospitals with electronic medical health records or admitting records actually import the demographics into eSP, as well as screen results for hospitals with high birth rates.

A question was asked about the involvement of the medical home team at the site visits. Barb and Vicki reported that it is unknown at this time what role they will play, if any in hospital site visits. The team will be assembled in April if CHSCs EHDI receives the grant. Vicki reported that they will be reaching out to physicians in many ways. They will provide an update to the committee in a future meeting after the workgroup meets.

**Guide By Your Side update (Susan)**

Vicki provided an update as Susan was not able to attend. Susan and the guides continue to meet with various entities serving children to let them know about family support services. Vicki reported that there have been more referrals in 2010 than in the past; however, it is still not as high as they would like. The program continues to look for a Spanish speaking parent of a child with hearing loss. We want to be able to provide that cultural aspect. Vicki said that they had a good lead but mom is very busy and did not want to take on more. She also stated that if a committee member knows of a mom or dad of a child with a hearing loss that might be good as a role model who can talk with other families, let any EHDI member know.

Vicki reminded committee members the National EHDI conference is in February in Atlanta. The National Center for Hearing Assessment and Management (NCHAM) is offering parent scholarships to help parents attend. One Iowa parent will attend on this scholarship; however, it does not cover all travel costs. Iowa has also submitted a second application for a parent scholarship in hopes of taking another parent.

**AAP EHDI Chapter Champion update (Dr. Sullivan)**

Dr. Sullivan was ill, so Tammy provided an update on her behalf. Dr. Sullivan has started to make contacts with smaller hospitals and hopes to do some EHDI educational presentations this spring. She is also working on getting information in a few newsletters. Tammy reports that Dr. Sullivan is also attending the national EHDI
conference which will give her the opportunity to network with other EHDI chapter champions who may have some good ideas to share based on their own experiences. Tammy noted that she is working on a newsletter article for the nursing journal and has recently been in contact with a few midwives. She said that they hope to include a goal in their upcoming CDC competitive grant which increases the work with midwives to decrease the number of refusals for home births as well as decrease the number of children who become “lost to follow up.”

Program Evaluation/Data Analysis (Jen)
Jen stated that the birthing hospital survey is out and she has received 51/82. She stated that when she receives all the surveys, she will report on the number of hospitals doing outpatient hearing screens that were not doing them previously.

Jen stated that there were two documents sent out prior to the meeting that summarize the results of the surveillance survey for hospitals and AEAs. If members have specific questions about the results, contact Jen Thorud.

Jen stated that the parent survey will go to test in the next week with home birth and hospital birth families. The survey will go out in the spring to 3000 parents of children born in Iowa during 2010. It will include home birth families, families of children who did not pass their initial birth screen but later passed an outpatient screened, children with hearing loss and children with normal hearing.

Agenda Items for April
- HRSA/CDC grant update
- CDC Survey update
- Lenore- Telehealth update

Next EHDI Advisory Committee Meetings
April 7, 2011
July 7, 2011
October 6, 2011