Early Hearing Detection and Intervention Advisory Committee Minutes
Thursday, April 1, 2010
10:00-3:00 p.m.
Location: Altoona Public Library, 700 8th St SW, Altoona, IA

Committee Members: Kathryn Baumann-Reese, Marcy Beisiegel-Clausen, Jane Borst, Valerie Caputo, Lucia Dhooge, Anna Dolezal, Susan Hagarty, Diana Hanson, Roger Hess, Lucinda Hollingshead, Jeffrey Hoffmann, Lenore Holte, Nick Salmon, Sally Nadolsky, Barb Khal, Bob Vizzini, Rebecca Young

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

Introductions & Announcements
- Dr. Amy Wallin and Mike Jorgenson resigned from the EHDI Advisory Committee
- Roger Hess will be retiring this summer from the AEA. Roger indicated that a replacement should be determined by next month. Roger was recognized with a certificate of appreciation at the meeting. Dr. Wallin and Mike’s were mailed. Dr. Shannon Sullivan is the new AAP Chapter Champion for EHDI
- Val Caputo is a new member representing AEA audiology. Val is with Green Hills AEA (Green Valley AEA 14 will merge with AEA 13 to be Green Hills beginning July 1)
- CHSC staff changes: Peggy Swails is Erin’s replacement for the HRSA grant, Susan Hagarty is Melissa Carlson’s replacement for Family Support and the Guide by Your Side (GBYS) program
- IDPH staff changes: Meghan Wolfe was hired as the IDPH-EA liaison. Jen Thorud was hired to perform data analysis for EHDI and conduct program evaluation
- Tammy handed our brochures produced by NCHAM in collaboration with individual states entitled, Communicate with Your Child. The brochures are available to hand out to parents of newly identified children with hearing loss. They include information on communication options, state and national resources available to parents of children who are deaf or hard of hearing
- Tammy let committee members know there will be a summary in the next newsletter regarding the survey results for the EHDI newsletter. The results were positive and as many readers review the newsletter electronically as those that read hard copies. Kathryn suggested we provide guidance in the next newsletter on how others can join the electronic notification distribution list.

Iowa Symposium for Hearing Loss: Impact on Children & their Families (Lenore)
- Every other year we apply for a grant to CDC to assist us with costs for a hearing loss symposium that is hosted by the EHDI program and Centers for Disabilities and Development
Iowa’s Early Hearing Detection & Intervention (EHDI) Program

every other year in the fall. The dates for 2010 are Sept 17-18 at Ankeny Marriott. Registration begins at 12:30 pm Friday. The symposium ends at 3:30 p.m. on Saturday. We are close to finalizing the program. One day registrations will be offered, but we are hoping that most professionals will come both days. CEUs will also be offered again.

- Friday events: Marilyn Neault- Friday afternoon Marilyn will speak about Auditory Neuropathy/Dsynchrony including management for screening programs and audiologists. HRSA EHDI will request funding through MCHB to cover her costs as the EHDI program would like to receive additional technical assistance from Marilyn following her presentation. Brian Grubb- motivational speaker who happens to be deaf and blind will speak Friday evening. Lenore will provide some interesting data she and Boys Town have learned from the Hard of Hearing Study. Amplification fitting will also be included in the talk. Emily and Nick will provide training on newborn hearing screening, tips and recommended follow up for screening programs. Dr. Kimberling and Dr. Prickett will speak about Ushers syndrome and management for families and providers.

- Saturday’s events are targeted to families. The day will start with a parent panel who will share their experiences of raising children who are deaf or hard of hearing. Vicki Hunting will give an update on NICHQ and services/supports in Iowa. Leanne Seaver - Hands & Voices national organization will speak on a topic (still TBD) relevant to family support (siblings is being considered). Susan Hagarty is teaming up with a behavioral psychologist from UIHC who is an expert on kids with disabilities. They will do a session on behavior management. Vicki and Marsha will talk about recommended practices in education. An audiologist from an AEA will speak about assistive listening devices. Barb Khal will do a presentation on medical home. Lenore noted that sessions may need to be combined to fit in the schedule.

- The symposium will be low cost (registration covers the cost of food only). $25-30/day. We are no longer looking for speakers for this year, but will entertain suggestions for our 2012 symposium. Birthing hospitals will be able to allow one nurse to come for free. Jane noted that letters should be sent to hospital administrators to encourage participation by hospital nurses. Lenore stated that the brochures should be ready by May 1st. The save the date postcards will be ready in the next week or so to be mailed. Tammy offered to put the postcard on the Web, as well. A message was included in the spring newsletter and will be included in the summer newsletter, as well. Contact Lenore or Sara Patkin (conference coordinator) mspatkin@yahoo.com with questions.

Guide By Your Side (Susan Hagarty)

- Susan attended national EHDI conference. She reported that she got many ideas from the Indiana GBYS coordinator. Referrals continue to come in slowly. The GBYS program is affiliated with Iowa Hands & Voices. Susan believes that AEAs have some reservation based on past experience with Iowa Hands & Voices and the fact the GBYS guides have not been visible in their region. Susan is scheduled to speak to the Regional Liaisons about Iowa Hands & Voices and GBYS at the next EA regional liaison meeting. In addition, Susan plans to meet with every guide and meet with AEA representatives. Susan’s goal is to increase the personal contact
between the guides to families and the guides to audiologists who make the referrals. This will hopefully help initiate the relationship needed for audiologists to be comfortable making referrals. Susan stated she is looking into the possibility of getting GBYS information out with the first follow up/re-screen. Some members of advisory expressed concern that providing referral at that time may be premature since many of the children pass their re-screen. Diana spoke of parents needing the information at different times, as well. Some parents are even overwhelmed when they first learn of the diagnosis while other parents want to know about all resources.

- Tammy inquired about the status of the GBYS brochures? Tammy shared that some AEAs and audiologists have said it would be helpful to have the brochures with their materials they provide at the point of diagnosis. It would serve as a reminder. HRSA EHDI staff said they would follow up on their status. Tammy said she would also put the brochure on the Web site when they are ready. Status update since committee meeting: GBYS brochure is in final review and should be printed within the next thirty days.
- CHSC EHDI has money budgeted for guides. Susan noted that if they do not have referrals, she would like them to get more involved in the community to remind the providers about the program.
- Susan reported that the states that are the most successful appear to be those states that include referral information sooner in the process. Susan said she believes audiologists have a responsibility to give the information when they feel it is best for families and revisit the referral at a later date because minds change over time and parents do not always know what they need. Susan shared her experience with her child.
- Diana currently speaks with the family regarding the GBYS program at the point of diagnosis or a follow up appointment regarding communication options. She gets a release and makes the referral to GBYS. Val offered to remind audiologists at the Leadership meeting in April about the importance of speaking to parents about the GBYS program and making referrals if the parents are interested. Marcy stated that AEA 9 does speak about family support. They make the referrals or the early intervention staff working with the family. The referral for family support may not always be to GBYS, but possibly another parent in the area or family support program. Tammy suggested that EHDI staff may also want to survey the audiologists to see what they are doing and how the EHDI program could help them make timely referrals.

Legislative Updates
- Hearing Aids and Audiological Services (Tammy)
  - Rep. Petersen put forth the hearing aids and audiological services bill this past session. The bill would have mandated hearing aids and audiological services be covered for state regulated insurance plans for children under the age of 21. Tammy noted that the bill made it out of subcommittee this year and would have been eligible for debate on the floor. She noted that this was the farthest the bill has gotten. There was more outreach and advocacy by families and providers at the capitol and in their home communities. The Iowa Child and Family Policy Center worked closely with Rep. Janet Petersen to
garner support. Tammy said there was also quite a bit of news coverage this year where there has not been in years past.

- The funding was cut in the fall when the governor ordered ten percent across the board cuts. The funding has not been restored at this time. IDPH continues to maintain a wait list through the claims provider. If the funding is restored, contact will be made with those families in the order in which applications were received. Tammy reported that Carrie Fitzgerald with the Iowa Child and Family Policy Center continues to work on this issue with Rep. Petersen. Diana Hanson and Kathryn Baumann Reese shared their experience in attending the subcommittee meetings. Diana noted that Dr. Waldron spoke at the meeting about the medical need. Diana stated there was no mention of the cost savings to education; only costs to the insurance companies.

- **Deaf Child Bill of Rights (Susan Hagarty)**
  - Susan reported that legislation had been drafted and includes language for children who are deaf or hard of hearing. Kathryn noted that they were working with a new legislator who is very supportive of the bill, but did not get it filed in time. She promised to introduce it early next year. Kathryn noted that this will give them time to speak with families and other legislators about the bill and how important it is for deaf or hard of hearing children.

- **Sign Language Interpreters (Kathryn Baumann-Reese)**
  - Kathryn noted that Marsha Gunderson has been working on training for sign language interpreters, etc. Kathryn noted that temporary licenses may evolve. There is discussion in the community about only those with a degree in interpreting being eligible for a temporary license.

**Public Health Informatics Institute Business Case Model** (Lucia Dhooge) - Lucia to review

- Lucia Dhooge presented a copy of the business case model, Effects of Integrating Child Health Information Systems. The document is also available at [http://www.idph.state.ia.us/hpcdp/family_health.asp](http://www.idph.state.ia.us/hpcdp/family_health.asp) (scroll to Business Case Model).
  - Public Health Informatics Institute based out of Decatur, Georgia. They worked with Iowa child health programs, including EHDI, to complete the tool.
  - The tool is used to for economic forecasting (EF). EF compares costs and benefits of integrating child health information systems. The tool puts the dollars to the cost of missing a child’s hearing loss or losing the child along the way during follow up.
  - Lucia noted the benefits for the EHDI kids are great. The benefits out weigh the costs when you are looking at EHDI programs.
  - Page 35 starts the beginning of the EHDI section of the report. The greatest impact is on children “loss to follow up/documentation.” Page 37 of the document shows where the data came from- national resources are used as the default, however states have the ability to include their own data when it is available. On page 39, table 13 shows the economic impact on EHDI program over five years. With a decrease in loss to follow up,
the total net effect is $41 million. Some assumptions are made — use of net effect— does not include the costs of building an integrated system. Those costs would be shared across multiple programs. Lucia noted that there are multiple estimates out there, but we don’t really know. Chart 15 illustrates family/private- effects on families, employers, insurers- negative medical care, - there are more costs to evaluate them and see them— early on costs. Lifetime productivity- tremendous benefit. Chart 16- government aspect- more money at the beginning because of more kids beings seen. Savings in special education- benefit for government. Chart 17- summary- effects on society- there are high net effects.

- If people want to use the slides for presentations- talk with Tammy and we can provide slides. Lucia will get more information for Susan Hagarty related to lifetime productivity savings - many of which came from NCHAM.

**EHDI program data** (Jen Thorud/Tammy)

- Iowa EHDI data is good in terms of getting babies in for initial birth screens. Our refusal and lost to follow up rates are very low for 2008 at three percent. Nationally the numbers are around forty-five percent. Our 2009 lost to follow up rates will go down as data cleaning continues. There are many children who are still “in process.” Tammy and Jen will be working on data clean up throughout the summer. Tammy provided an example of a data entry error that could lead to a child being categorized as missed when they were not.

- Jen reported that our numbers of children diagnosed with hearing loss is going up which is most likely due to better reporting. Tammy reported that home births make up a large proportion of the refusals which is consistent with the refusals received from the metabolic program. If home birth families do not refuse, many are lost to follow-up. Tammy has been working with the vital records program to obtain phone numbers so those families can also be contacted by phone. She hopes to have the numbers available in April. Currently, all birth packets include a letter from IDPH EHDI with information about the importance of obtaining a hearing screen and where they can obtain them. In addition, all families receive a letter once they file for a birth certificate. Tammy is also working with vital records to revise the birth worksheet to include the name of the child’s PCP.

- In relation to the 1-3-6 goals, we are doing great getting babies screened by one month; however the preliminary numbers for getting children in for diagnosis are around fifty percent. In July EHDI personnel intend to present our early intervention numbers for 2008 and preliminary numbers for 2009. Jen showed a slide on state miss/refer rates by hospital level. The slide shows that level III hospitals are doing well at meeting the state goal of six percent. All level III hospitals are under the state goal. The level II hospitals are slightly above the state goal of six percent at eight percent and level I hospitals are consistent at thirteen percent. Tammy talked about some of the reasons for higher refer rates. There are level II hospitals with refer rates as high as twenty-three percent and level I hospitals with refer rates as high as forty percent. Jen reported that over the last few years, all hospital levels are doing well at meeting the state miss rate goal of one percent.
Jen talked about outpatient hearing screens. Over ninety percent of the children missed or who did not pass their birth screen pass their outpatient hearing screen. This shows the importance of getting babies screened prior to hospital discharge or within one month which, in turn, would allow more time to get the child back for a diagnostic assessment. The programs that are the most successful (low loss contact) are those hospital programs that arrange the outpatient hearing screen prior to hospital discharge, either at their hospital or another location such as the Area Education Agency.

Lenore said she would like to see the data on the average age of identification for confirmed hearing loss. Tammy reported that they would have the ability to report this at a later date when audiologists are reminded to utilize the section on amplification because it asks for date of diagnosis. Right now the numbers would not be accurate. Because this cannot be readily reported in eSP, Lenore volunteered to have an audiology student work on this if the student could be given eSP access. Tammy will work with Lenore to make this happen over the summer. Lenore also asked if CDC has those numbers available.

National Initiative on Children’s Healthcare Quality (Vicki Hunting)

Vicki presented a Power Point presentation which provided a summary about NICHQ, its purpose, who has been involved in planning, testing and implementation. This project is currently looking at a small group of approximately one hundred babies at Iowa Health DM. The project started gathering data in June and the data in the presentation is through December. Vicki explained that the EHDI program is looking at a number of performance measures - many relating to the 1-3-6 goals. Vicki shared that preliminary data shows that some of the small changes being made have shown improvement in the data.

Vicki reviewed the positive outcomes achieved from participating in the project: development of a DRAFT hearing healthcare map (although IRB process is inhibiting testing with families), auto call reminders, making follow-up appointments before discharge, blocking time for ABR screens, confirming PCP knows baby is going to their practice. Barriers include: time commitment and tracking tool provided by NICHQ. Lessons learned: IRB process takes a long time and follow up. Next step in the process: looking past rescreen to diagnostic assessment, planning to integrate lessons learned throughout other hospital programs and educate PCP’s about their role in the EHDI system.

Vicki solicited volunteers in the room to work on a PDSA (Plan, Do, Study, Act) to develop and test a process map for primary care providers. Vicki shared copies of maps already produced and available on the AAP website, Indiana and NCHAM. Vicki explained we need to hear from physicians, providers, and ENTs about what they want or need to know to assist families? Dr. Hoffmann’s thoughts: If physicians who are using electronic medical records could have this incorporated into their electronic medical records system that would be best. He noted that most offices are working towards that, but are not there yet. Not all systems allow you to flag results, etc. In the meantime, suggest the use of a checklist that is brief. Dr. Hoffmann referred to a
laminated 8 1/2 by 11 card provided by the immunization program. Dr. Hoffmann suggested that the program continue to use the different provider newsletters as a voice for information and refer to research or resources. Dr. Hoffmann agreed that if other states have a checklist, there is no need to reinvent the wheel. Most physicians/practices will accept it. Another recommendation was to send out a postcard campaign which emphasizes the importance of not waiting to get babies screened.

- Kathryn suggested we work with a hospital that is smaller, serving low income families, etc as it will pose different challenges. Tammy noted that we are in the planning stages to work with a public hospital. Tammy noted that she and Nick have already worked with this hospital to overcome some of the barriers that Kathryn spoke of.

**EHDI program evaluation** (Jen/Tammy)
- Jen and Tammy are in the beginning stages of planning EHDI program evaluation for the next year. They have been working with their CDC partners who are excited we are evaluating the system, including processes. In the next month some of you will be called upon to serve on steering committee which will help guide our work over the next year.
- In addition to program planning, Jen and Tammy have revised the program evaluation tool, including program indicators. The tool has been organized into three tiers. The first tier includes those indicators related to CDC and HRSA grants, data requirements and state goals we think are important in monitoring the status of the EHDI system related to meeting the 1-3-6 goals. The second tier includes “nice to know” indicators that also tell us something about our system, but may not be indicators that need monitored yearly. The third tier includes indicators that may also be nice to know or those that the EHDI program is not able to track at this time. Jen asked that advisory committee members look through the second tier indicators to see if they think there are indicators on the second tier that should be included on the first tier or indicators that should be moved to the third tier. Jen will then provide updates on the first tier indicators a couple of times per year. Comments should be sent to Jen, jthorud@idph.state.ia.us or Tammy, tohollea@idph.state.ia.us by April 30, 2010.

**Wrap up**
- Agenda items for July
  - NICHQ
  - Data and performance indicators/program evaluation
  - GBYS
  - Physician PDSA
  - Update on assessment revisions in eSP

**Next EHDI Advisory Committee Meeting**
- **July 1, 2010, Room 201 at Lucas State Office Building**