Early Hearing Detection and Intervention Advisory Committee Meeting Minutes
Thursday, July 11, 2013
10 – 3:00 p.m.

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

Members Present: Gretchen Hageman, John Cool, Kathy Miller, Linda True, Marcy Beisiegel-Clausen, Marsha Gunderson, Sally Nadolsky, Teresa Hobbs, Valorie Caputo, Lenore Holte, Lucinda Hollingshead, Lauren Binzer, Jill Simonson, Nick Giuliani, Dr. Jeffrey Hoffman.

Staff Present: CHSC: Leslie Huber, Vicki Hunting, and Susan Rolinger; IDPH: Tammy O’Hollearn, Esha Steffen, and Jinifer Cox

10:00 – 10:30 Introductions & Announcements
EHDI Advisory Committee Member Changes (Tammy):
Each committee member is asked to serve a term of three years. Members may continue to serve longer at the request of the IDPH director unless their absence at meetings exceeds attendance policy.
• Steve Sword and Michelle Vaccaro have completed their terms. Steve has been on the committee since its inception and Michelle served one term.
• Lucinda Hollingshead and Bob Vizzini requested a second term.
• Current opening for member from Iowa Hospital Association
Tammy indicated that the requirements in the charter regarding attendance, voting, etc. will be added to the EHDI administrative rules when they are opened in the future.

Deaf adult recruitment (Kathy):
Kathy noted they are currently recruiting for a panel of deaf adults and students. She will provide more information about their presentation at a later date. If you know of someone, please contact Kathy directly.

GBYS Webinars (Leslie):
• First webinar scheduled to take place in July. Leslie said Kathy was gathering a panel of deaf adults to share their experiences. A basic set of questions for each panelist has been developed. Additional questions may follow from the audience.
• Dr. Sullivan volunteered to present in the future. Other topic ideas or persons interested in doing a webinar, please contact Leslie Huber.
Medical Home Toolkits (Leslie):
- Medical home toolkits were mailed to 605 Primary Care providers at total of 112 addresses. This covers the PCPs of 77% of all Iowa births during the period of 1/1/2011 to 4/1/2012.
- The intent was to provide easy access resources about hearing health.
- Feedback from the survey enclosed in the toolkit has been difficult to obtain. A total of three surveys were returned to date. Requests for feedback have been sent by Facebook and Twitter on AAP.
- Comments include:
  - “Will look through it when I need it.”
  - “Obvious hard work – nice job! Thanks for loving our children – our future!!
  - “We do newborn screening at two weeks and then at eight weeks, then refer to the local audiologist. But will keep information in case it is needed for GBYS. Thanks”
- Birth hospitals received a slightly different toolkit
  - Sent to the EHDI contact.
  - UIHC will create a newborn hearing channel for the Loss & Found video and a box section of the patient library designated for hearing.
  - Other hospitals requested more copies of the video and the reference card.
  - Will ask how each hospital is using the video when we do our yearly survey to update contact information, referral, equipment, etc.

Hearing Loss Symposium (Lenore):
- Next EHDI symposium is planned for September 2014.
- Funds (approximately $20,000) are needed to keep the conference going.
- Lenore spoke about a couple of funding opportunities she is exploring. Please contact Lenore Holte for possible funding options at lenore-holte@uiowa.edu.

Bullying Article (Vicki):
- Vicki shared an article on bullying, “Audiologists Screening for Bullying Problems”
  - According to the CDC, one in three children reports being bullied, and that children who have disabilities are up to 75% more likely to be bullied than children with no disabilities.
  - Important to discuss this topic. Pediatricians and other health care providers have developed protocols to screen for bullying problems.
  - To read details on results of a September 2012 survey, a proposed screening protocol and suggested IEP goals, please request a copy of the article by contacting Esha at esha.steffen@idph.iowa.gov
10:30 – 10:45

National EHDI Conference (Iowa EHDI Team)

Members shared their experiences about national EHDI conference:

Tammy: Look forward to the conference each year because it is an organized opportunity to learn about other state programs and how they may be doing business, learn about best practices and how those are being implemented, latest research and networking with parents and providers from all walks of life.

Susan: Great meeting; a couple of parents were able to attend the national meeting this year. Susan noted she presented at the conference and networked with a lot of parents and providers. She noted she got some ideas to explore regarding GBYS programming.

Vicki: Enjoyed the meeting, great attendance!

Esha: This year’s national meeting offered a number of great sessions that included information on different short-term follow-up procedures performed in other states. Benefited from two particular sessions in which Texas and Massachusetts EHDI programs shared their lessons learned, their successes and challenges with follow-up procedures, lost to follow-up rates, re-screening etc. As compared to other states that are struggling with reducing lost to follow-up numbers, Iowa seems to be more successful with our strategies and modified short-term follow-up processes in decreasing our lost to follow-up/documentation rate. One panel presentation that Esha enjoyed the most was “lessons to learn from Deaf College Students” that was held towards the end of the first day. They shared their experiences including support from their family members, general perspective on life, and how their positive outlook on life helped them become highly successful individuals. Overall, Esha said it was a great learning experience!

10:45 – 11:15

Short-Term Follow up (Esha)

Esha presented on the short-term follow up (STFU) analysis for 2012. The primary purpose of follow-up, tracking and reporting is to ensure that all babies get screened and receive timely services, if needed. It also provides the basis for measuring the program’s effectiveness, progress, outcomes, strengths, and weaknesses. Some of the follow-up activities performed by IDPH EHDI each month include contacting birthing facilities for any missing babies or incorrect data entry in the EHDI database, collecting & entering results from facilities that are still using paper forms, and making sure babies that are born out of hospital (home births, etc.) or transferred to an out-of-state facility receive a hearing screen in a timely manner, etc. Approximately, 250-300 follow-up phone calls are made by the IDPH EHDI team each month.

Here are some of the main key points from the PPT:

- In summary, the EHDI program at the Iowa Department of Public Health followed up on a total of 5280 babies in 2012. The breakdown of each category is as follows: Family & Healthcare Provider Follow-up (23%); NICU (56%); transfer (5%); Out of state (6%), Iowa Health (9%) and Home births (1%).

*Note: This number (5280) includes same babies that may be in the NICU for several months and therefore, get counted multiple times. Total number of actual babies referred to IDPH EHDI is 3585.*
Total babies that are still in-process: 5 (these babies are considered medically fragile that may still be in the NICU and are being watched until they receive a hearing screen).

Lost to follow up/documentation (Based on STFU only): 160/3585=5% (Preliminary).

The PowerPoint Presentation is available upon request. If you’d like a copy of the slides, please contact Esha Steffen at esha.steffen@idph.iowa.gov

11:15 – 11:30

GBYS Update (Susan)
Linda reported they have plans to host their first monthly “Family to Family” conference call with guest speaker Linda True, pediatric audiologist with Hearing Associates in Mason City. Susan reported they have a coffee time family chat scheduled for the Des Moines area at the end of July.

Susan noted that there have been at least nine babies diagnosed with permanent hearing loss in 2013. Calls have been made to each family from GBYS and five of those families were referred for parent support services, three were enrolled in the GBYS program and are actively participating. Susan reported that out of the 51 families diagnosed in 2012, 18 are enrolled in the GBYS program. She also noted that 24 of the families were contacted more than once. After no luck by phone, letters were mailed. Susan commented she was able to help a family (foster parents) of a child she called on.

11:30 – 12:30

LUNCH

12:30 – 12:45

Midwife/Home Birth Outreach (Tammy)
Tammy provided an overview of the work that Lenore’s student, Caitlin Sapp had done to date such as hosting a focus group with a couple of midwives, calling midwife groups to explore doing a presentation and creating a catchy poster regarding the importance of screening for hearing loss. Tammy shared information she and Caitlin gathered from the midwives during the focus group.

Most recently Caitlin called on a mom she knows that had her child at home and whom has a significant hearing loss to tell her story. After she did that, Tammy asked if it could be used in home birth packets that are sent out and letters to families of children born at home who are hard to reach. The mother agreed. Tammy shared the mother’s story. Caitlin put together an educational letter, the hearing screening poster and included this mother’s story and then sent it to all midwives across the state. Tammy reported that one of the midwives called for more information and another wrote a nice thank you note regarding the packet of
information. She noted she planned to hang it in her practice restroom! Tammy noted that anecdotally it appears more home birth families appear to be taking their children for screens but she will be doing analysis in the coming year to see if the data supports those findings.

Esha talked about the difficult calls she has faced with some home birth moms and she has had some success in some cases and no success in others.

12:45–1:00  
**Risk Factors Study (Amy Carlson/Lenore)**

Lenore presented on “Risk Factors Associated with Early Childhood Hearing Loss in Iowa.” The main objective of this study was to investigate the relationship between the risk factors selected by the Joint Committee on Infant Hearing (JCIH) and the presence of hearing loss in children under the age of three years. All available information was collected from the EHDI database (eSP™) for each child born in Iowa between 2007 and 2010 regarding their hearing sensitivity and risk factors. Please note that no identifying information was gathered. The study mainly focused on prevalence of early childhood hearing loss in Iowa; frequency of reported risk factors; and risk factors associated with permanent congenital hearing loss and delayed onset hearing loss, etc. For information about this study, please contact Lenore Holte at lenore-holte@uiowa.edu.

Lenore will present data on 2010-2012 babies in 2013.

1:00–1:30  
**Outcomes of Children with Hearing Loss Study (Lenore)**

Lenore presented on the “Outcomes of Children with Hearing Loss” (OCHL) study. This study is an NIH-funded, multi-center study designed to explore the developmental outcomes of children who are hard of hearing (mild to severe hearing loss). Following are the key points from the PPT:

- Outcomes data on communication, academic, and psychosocial skills are gathered in an accelerated longitudinal design; data on service provision is collected, including type, dosage, and specialty of provider.
- Normal-hearing control group; No developmental disabilities; English first language.
- Results: Of the independent variables, only mother’s education was found to be significantly related to the ages of first diagnostic audiologic evaluation, hearing loss confirmation, and hearing aid fit.
  - There was no significant relationship between the predictor variables and the age at which the child entered early intervention.
  - There was no relationship between the predictor variables and the time that elapsed between confirmation of hearing loss and entry into early intervention.
• **Reported reasons for delays:** Multiple screenings, recurrent otitis media, family told by the PCP to wait until behavioral testing was possible, difficulty obtaining appointment for ABR, medical clearance for hearing aids or hearing aid fitting.

• **Conclusions:**
  o Many families accessed care following newborn screening within recommended time frames. Specific barriers were identified, and these appear to be addressable through improved systems, services and educational efforts.
  o In a group of children who are hard-of-hearing, higher maternal educational levels were significantly associated with earlier confirmation of hearing loss and fitting of amplification. Severity of hearing loss was not.
  o Public awareness campaigns about newborn hearing screening and the importance of good hearing for speech and language development must continue to be developed, with particular emphasis on underserved communities.
  o There remains confusion on the part of providers and families about the presence of hearing loss in infants and toddlers who display awareness of sound. Educational resources and training should address this specific gap in understanding.

*Follow up Questions/Comments:*

Q. Funding for Hearing Aids: Was that renewed this year?
A. There is EHDI funding available. An announcement was recently sent to providers. The funding announcement is also advertised on the EHDI website with information about who accessed the funding in previous years, etc.

Q. How can we educate moms about newborn screening?
A. Some suggestions included social media: Facebook, Twitter. The PowerPoint Presentation is available upon request. If you’d like a copy of the slides, please contact Lenore Holte at lenore-holte@uiowa.edu

**1:30 – 2:15 Iowa Physician Survey Results (Tammy)**

Tammy shared a PPT on Iowa Physician Survey Results. Following are some of the highlights:

*Purpose of the survey:* Understand the degree to which medical homes are engaged within EHDI systems; update our understanding of physician attitudes and knowledge regarding newborn and early childhood hearing screening and follow up; and identify strategies to support physicians in their role in EHDI.
Methods: A hard copy of the survey was sent to physicians that serve Iowa’s children, including ENTs. The letter also included a hyperlink in case physicians wanted to respond to the survey online. A postcard reminder was also mailed 7-10 days later.

Response rate: 925 surveys mailed with only 6 surveys returned as undeliverable; only 76 (8%) surveys were returned. Other states had similar response rates. Only 2 surveys were completed online for Iowa and this was the same experience other states had.

Lessons Learned: Difficult to obtain physician emails and some do not want the contact through email; piloting revealed a minority will use online option; physicians are inundated with surveys; a small number of physicians expressed interest in results.

Next steps: Further analysis of Iowa data vs. national data; meet with Dr. Sullivan and Dr. Hoffmann to discuss strategies; DSHPHWA sub-committee working w/AAP to increase provider knowledge and best practices; share results with PCPs (pediatricians, family medicine, ARNPs); and continue to increase communication with PCP’s and parents.

The PowerPoint Presentation is available upon request. If you’d like a copy of the slides, please contact Tammy O’Hollearn at tammy.ohollearn@idph.iowa.gov

2:15 – 2:45

Family Resource Guide – Audiology Section Review/Suggestions (Leslie)
PowerPoint provided by Lauren Binzer (CHSC Volunteer). The slides are available upon request; if you’d like a copy please contact Leslie Huber at leslie-huber@uiowa.edu.

Goal of Update:
- Divide the guide into separate downloadable sections from Parents Website
- More white space and pictures
- Graphs and tables to present information
- Simple language and make sure to define terms
- Include hyperlinks within each section to resource websites i.e. Early ACCESS, GBYS, etc.
- Replace logo with updated EHDI logo

Comments for the Resource Guide from the summer 2012 EHDI Advisory Committee will be incorporated into any revisions. Leslie requested volunteers from the committee to review/edit, please contact leslie-huber@uiowa.edu if interested.

2:45 – 3:00

Wrap Up/Sharing
Next meeting is October 3rd, 2013