Early Hearing Detection and Intervention Advisory Committee Agenda
Thursday, October 11, 2012
10 – 3:00 p.m.

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

Members Present: Marsha Gunderson, Linda True, Steve Sword, Kathy Miller, Shannon Sullivan, Valorie Caputo, Jill Avery, Diana Hanson, John Cool, Lindsey Crawford, Valerie Christianson

Staff Present: CHSC: Barb Khal, Vicki Hunting, Susan Hagarty, Leslie Huber and Debra Waldron
IDPH: Tammy O’Holleam, Esha Steffen, and Sylvia Petersen (EHDI intern)

10:00 – 10:15 Introductions & Announcements
- EHDI personnel updates: Leslie Huber was hired as the long term follow up coordinator. She starts working full-time on 10/22/2012. She has a degree in nursing and her master's in business. She was previously the executive director at Children's Center Charity.
- Marsha went to an interpreter conference; tips for an interpreter-friendly presentation

10:15 – 10:30 NAD Conference (Kathy)
Kathy was at the conference but focused on the NAD rather than the EHDI part
Learned a lot about different cultures, diversity, complaints (different between east side and west side), a lot of things related to the by-laws, suggested a visual display (e.g. in a gas station) to communicate how much something costs (rather than having to write it down)

10:30 – 10:45 Iowa Symposium on Hearing Loss (EHDI Team)
- The symposium was well-attended. There were about 120 participants. Survey monkey for feedback on the conference was sent out.
- Members shared their experiences with the committee. Some of the comments include:
  o Diana thought round table was great; conference as a whole was good; only question was with the interpreters--positioned right in front of the screen, would be better if they were closer to the speaker.
  o Esha thought it was a great learning experience; attended one of the round tables, was able to learn about the deaf culture: the lifestyle, daily routine, etc. Overall, it was a very positive experience.
Marsha--most round table sessions went well, a few were not well attended (Iowa School for the Deaf Summer Program); there was a lady from Ohio to determine how to improve their EHDI program.

Linda--unable to attend round tables; colleague Rachel D. thought they were very good, was her first symposium and she was very impressed; Linda was impressed by the diverse population who attended this year as opposed to two years ago.

Leslie--very broad overview of the issues, from the EHDI summary and Mark's presentation; enjoyed the round tables, possibly too much selection because you couldn't go to all of them.

Susan--great symposium, speakers; glad a lot of families were there, would have been nice to identify them somehow (e.g., on nametags); round tables were excellent; impressed by the variety of people who stopped by her table, it was the right amount of time.

Kathy--enjoyed the presentations and round tables; several families were encouraged to get involved; it's hard for families to interact with hearing families, so encouraging families to interact with deaf people would be a good thing, especially for their children.

Vicki--PowerPoint presentations online were new; impressed with the diversity of attendees, every group was attended in some way; enjoyed round tables- possibly too many tables; enjoyed having NE and IL EHDI staff there.

Shannon--unable to attend a lot of the symposium; enjoyed talking to out of state people and learning what they have been doing to get EHDI education out to providers; diversity of attendees.

Valerie C.--hoping for more information from presenters on how to bridge the gap between info and practice; attended Pit Stop and heard a presentation on the OCHL that would have supplemented Lenore's presentation well; liked the round tables, great way to get info in a short amount of time, but some were loud so either less tables or more spread out; learned new things from Diana.

John--wonderful symposium; the panel was an excellent idea, would it be possible in the future for the moderator and the panel to get together at lunch? Some of the questions were hard for the panel members to respond to on the spot.

Tammy—asked if the panel needs to be on the first day. Some professional folks were unable to make it to the second day; good info that comes from families

- Marsha--on the fence about it being geared towards professionals and geared towards families; we should try to gear it to both for both days.
- Tammy--even trying to combine, it happens anyways, and it is difficult to balance.
- Leslie--it would be better if either the panel or round tables were on Friday
- Linda--likes the idea of having the panel on Friday; it would be really helpful for professionals to hear that side outside of the practice.
- Susan—suggested putting the panel early on Saturday for the professionals who stay over to go in the morning.
Lucinda–loved Karen’s session; Nick and Emily's session; really liked the opportunity to visit with the exhibitors

Q. How was the symposium marketed?
A. The symposium was announced in several different ways including:
   - Iowa Hands and Voices have a distribution list of families, professionals, and educators, and mailed the brochure to them.
   - EHDI website
   - All EHDI Advisory Committee members were advised to share with their colleagues
   - All hospitals were notified

Tammy asked the members for suggestions for the next symposium.
Steve commented, “The licensure board has an Excel spreadsheet of all audiologists, could use this to send to audiologists.”

Tammy also asked the members for suggestions for speakers. It would help to book national speakers for the next symposium as early as possible as their schedules get full quickly.

10:45 – 11:00 Update on the Deaf Child Bill of Rights (Kathy Miller)
- Deaf and hard of hearing children's education bill of rights. On August 4th--many attended a few deaf and one hearing from DSCI (?)
  - Explained bill of rights, no changes or suggestions
  - Jerry Sider plans to contact the department of education to see if they will review the bill

Q. Do you anticipate a bill will be put forward in the next legislative session?
A. Probably not till 2013, maybe 2014

11:00 – 11:15 Cultural Competence Community of Learners Update (Susan)
- Get together via phone, worked well to involve Kathy with the process.
- Each month one of the states does a cultural overlay of their state--learned a lot from each other (so far CA and NJ)
- CA--Populations served: Adult population Caucasian is not higher than 50% but still highest; Hispanic is the highest population in children.
- NJ--a lot more like IA
- WI--plain clothes population, similar to Iowa Amish/Mennonites.
- A lot of personal introspection, challenged to look at our own culture, beliefs, and perspectives.
- IA will do cultural sharing in November
11:15 – 11:30  Update on the EHDI Website and Logo (Tammy)

- **EHDI Logo**: Voted on a new logo in July of 2012. The new logo is included on the first page of this document.
- **EHDI Website**: Work in progress. We are currently working on designing the home page and parent page. We'll provide another update in the next meeting.
- **Home Births Update**: We continue to struggle with this population in getting hearing screens. One of Lenore Holte’s students, Caitlin, is working with us. She is looking at home birth data. Denise Wheeler (midwife and works in Bureau of Family Health) provided some contacts and ideas. We also invited some peers in to a meeting to provide insight. Caitlin will put together a presentation for the midwivery conferences and put together resources.

**Q. Is the reason the home birth families are not going in because they don't have the information, or is there another reason?**

**A. Tammy**—they do receive the information; e.g. Dana provided information on what midwives do—provide birth packet with letter and brochure, she sits down with the family and goes through the entire packet, and then follows up with them after the birth; some midwives may assume the PCP will address it with the family. Also, we can't always tell who the midwife is and some have their own opinions about hearing screening (e.g. "big brother").

**Q. In Amish communities, there are no telephones. Hearing loss is higher in that population. Is there a possibility of convincing the elder to encourage families to get hearing screens?**

**A.** There are two Amish communities we are working with elders. They are open to us providing hearing screening. However, each community was extremely different but both of them were supportive. We are still trying to figure why it is successful in some areas and not in others; working with Davis County area to get the screenings done.

**Q. How are parents notified whether their children passed or failed?**

**A.** Hospitals include hearing screen results in the birth packets and some use printable letters from the database to notify the parents. It is required by law that hospitals share hearing screen results with the families. They provide a written copy of the results to the families and to the baby’s primary care provider as well. Hospitals are also encouraged to explain hearing screen results verbally to the families prior to the hospital discharge.
Q. Is there a way to educate nurses?
A. Education is provided to nurses during hospital site visits and through the Newsletters (EHDI & nursing newsletter); continuous training is provided to the nurses due to staff turnover.

Marsha shared there is a hearing health seminar on November 10, 2012. Patients with cochlear implants will be sharing their experiences at that seminar.

11:30 - 12:30  Lunch on your own

12:30 – 12:45  Deaf Iowans Against Abuse (Jennifer Upah)

Will be discussed at the next meeting

12:45 – 1:00  Short Term Follow Up (Esha)

2011 Data Analysis: The handout shared at the meeting contains the 2011 data analysis that includes tables and charts that show a detailed report of the total number of referrals received by the Iowa Department of Public Health. Referrals are broken down into a few different categories: NICU, Out of state, Transfers, Family follow up, Home births, etc. Please see the handout for more details.

Q. What does the category “out of state” refer to?
A. Out of state category refers to “Children that are born in Iowa but live out of state.”

Q. What does the category “Transfers” refer to?
A. Babies born in a hospital and then transferred to a different facility in another state.

Q. Would long term follow up babies be at the point where they would be coming to the ENT?
A. Yes.

Q. Linda receives copies of the letters we send to physicians and attempts to get families in--how many no-show appointments should they follow up on?
A. The decision is up to the provider; we have a protocol that we follow as to how many contacts we make before we move the record to "lost contact". Short term follow up calls the families twice, notifies the primary care provider and if no response received from the family then sends a letter to the family. Sometimes communicating with PCPs is helpful; e.g. if the family is not showing up to well child visits as well then it shows that family has a history of non-compliance.
Update on Short-term follow up Processes:
- STFU referrals (family follow up) changed to biweekly instead of monthly since May.
  - Outcome: It would us meet our goal of screening and re-screening by 1 month of age.
  - This has helped us catch kids between their two-week and one-month well child visit at the PCPs office as opposed to two month well baby appointment.
  - Referrals are sent out to the AEAs twice a month, around the 10th and by the 30th of each month instead of once at the end of the month
  (A huge thanks to Jinifer Cox (EHDI Program Assistant) for preparing the spreadsheets and Sylvia Petersen (EHDI intern) for her assistance with family/PCP phone calls.)

A closer look on children that were moved to “Lost Contact” in early 2012:
- Recently, I started paying close attention to our Lost Contact Kiddos in 2012. The category of “Lost Contact” refers to children that we have not been successful in bringing them back for a hearing screen/re-screen even after several attempts have been made (phone calls have been made to the families/PCPs, AEAs/ENT clinics/hospitals have tried but have had no success and they are moved to lost contact). In most cases, families are aware since they have received several phone calls and letters from IDPH/AEAs/Hospitals but they are choosing to not make a decision at this time.
  - Contacting the PCPs one last time and requesting them to talk to the families to see if families have any intentions of getting the screen done. Encouraging families to make a decision by either refusing or getting them to schedule an appointment at the earliest.
  - So far in 2012, out of total “lost contact” kiddos- 11 kids have come back in and have had normal hearing, and two children whose parents refused to get the screen done.
  - Hoping to see a great reduction in our overall lost to follow up/documentation number in future.

Best Practices and Database Training:
- Great River Medical Center in West Burlington on best practices and eSP™ (EHDI database) on 09/20/2012.
  - About 10-12 of their staff attended: Included two Audiologists, nurses, and technicians (screeners).
- Training involved EHDI Goals of 1-3-6, national and state statistics, discussion on quarterly hospital progress report, screening tips, and data entry into eSP™.
- Great learning experience for both parties; received positive/helpful feedback.
- Hoping to continue providing training across the state especially to those hospitals that have higher refer/miss rates or increased number of data entry errors.

1:00 – 1:15  **Long Term Follow Up (Vicki)**

Long-term follow up refers to children that did not pass the outpatient hearing screen and are in need of diagnostic assessments. We’ve been short staffed over the past year and are currently trying to catch up. We are focusing on babies born in 2011. There were a total of 219 children in 2011 that needed follow up. We are contacting ENT or PCP to see if there is any more information. Out of 219 kids, 29 (13%) got back in and passed; and 12 are identified as lost (same issues as short term follow up--can't be reached or passively refusing).

**Case management:**
- At least 2 contacts per child; up to 24 (this includes email, phone, etc.)
- 38 kids hadn't been anywhere, 20 now have seen someone
- 40 unilateral/bilateral hearing loss--expected to go up
- 166 in process-working to reduce this number!
- 64% of contacts via phone
- 19% through letter
- 12% email
- 5% fax
- 24% PCP
- 24% families
- 22% audiologists (educational and private)
- 20% call backs

Most calls have been made to professionals; if unable to get anywhere then will call the family. We are coaching ENTs and PCPs to talk to the families either via a phone call or during well child visits. AEs slow to respond during the summer. We are also looking at progressive lost kiddos. Physicians are still having issues with no-shows. Some offices are surprised when they receive a call because they have no idea the child didn't pass an outpatient screen. We had an issue with a physician dismissing a failed outpatient screen because the child "responds well to noise and parents don't have any concern of hearing." The phone calls provide a reminder for providers to continue with follow up. Medical professionals need more education on hearing issues in general. We will be wrapping up our follow up soon for babies born in 2011 and will start on 2012 babies!
Q. What happens to kids who have passed their hearing screen but get ear infections and then have hearing loss?
A. Information gets on the record and they are followed to ensure they receive proper follow up. Risk factor letters are sent out to the primary care providers of those children who have passed their initial hearing screen but have risk factors indicating that they need proper monitoring (e.g. family history of hearing loss, babies on ototoxic medications, etc.).

1:15 – 1:30 Guide By Your Side (Susan)
It has been successful to call parent to parent. Parent compliance is the most important factor in getting the child back in. Many parents seem resistant or noncompliant because a healthcare professional has told them not to worry about it.

GBYS--training at symposium; referrals have gone up d/t being able to focus on those diagnosed in 2011. In our survey, I asked parents if they have had contact with a parent of a child with hearing loss and none of the parents reported they have. I feel it’s a great way to connect; it's not happening in the early stages anywhere else. No parent has questioned why we are calling or how we got their information. Hands and voices is international so even families who move out of the area will have support.

Q. It seems like a lot of people attended the GBYS table at the symposium. What questions were they mainly asking?
A. Referral process, eligibility criteria, etc.

1:30 – 1:45 EHDI Toolkit (Vicki)
Toolkit includes:
- Poster for office with 1-3-6 goals
- Poster for lobby encouraging knowing about the status of their child's hearing
- Algorithm developed by AAP that gives the steps for referrals; checklist; popular PCP codes
- GBYS brochure
- Early ACCESS English and Spanish brochures
- Loss and Found DVD
- Letter signed by Gretchen Hageman and Debra Waldron regarding the importance of medical professionals and a letter from Susan about families
- Lanyard for visual reminders and has a USB drive and card--"undetected hearing loss is a developmental emergency"; 1-3-6 goals. Flash drive contains three folders: Medical professionals (more extensive list of codes); links to resources; Parent support; Early ACCESS

The biggest expense was the DVD (HRSA); lanyard, flash drives, and printing; the rest was donated.
Physician Survey: EHDI will also be sending out surveys to providers through AAP to determine their understanding of the EHDI program. Hard copies would be mailed out to about 1,000 physicians. Also will plan to send out a survey with the toolkit.

Q. Does the survey include any questions related to how long physicians wait to refer a child on for rescreening?
A. There are a few questions that will cover that.

1:45 – 2:45  Family Resource Guide (Vicki)
We are currently in the process of forming a team to work on the guide. Vicki requested if any of the committee members are interested in working on it, please email Vicki Hunting at vicki-hunting@uiowa.edu

2:45 – 3:00  Wrap Up/Sharing
Agenda Items for January 10, 2013
- Please let Tammy know what ICN sites you would like to use
- Case management module demo? (The case management module is a good way to track contacts, follow up status/details, and any other important information. It captures referrals to Early ACCESS, GBYS, as well as families who decline the testing.
- Long-term follow up update on 2011
- Home birth updates
- Feasibility study update

Next EHDI Advisory Committee Meeting: January 10, 2013 from 9-12pm (ICN)
Please provide 48 hours’ notice for any special accommodations needed to participate in this meeting.