Early Hearing Detection and Intervention Advisory Committee Meeting Minutes
Thursday, April 3, 2014
10 – 3:00 p.m.

Location: West Des Moines Public Library, 2nd floor conference room

Members Present: Gretchen Hageman, Kathy Miller, Linda True, Shandra Sarasio Meyer, Marsha Gunderson, Mary Stevens, Bob Vizzini, Sally Nadolsky, Teresa Hobbs, Valorie Caputo, Susan Rolinger, Caitlin Sapp (Audiology Student)

Staff Present: Tammy O’Hollearn, Emily Andrews & Esha Steffen

10:00 – 10:15 Introductions & Announcements
Members introduced themselves.

EHDI Advisory Committee Member Changes (Tammy)
Shandra Sarasio Meyer joined the Advisory Committee in place of Marcy Beisiegal-Clausen who will retire at the end of this school year. Shandra is a teacher of the Deaf and Hard of Hearing at Area Education Agency 267. Welcome.

Family Resource Guide (Tammy)
Revised English family resource guides have been published on the EHDI website. New copies are available on the website if members are interested. The document can be printed in its entirety or certain pages. Feedback is welcome if members notice additional changes that need to be made.

Hearing Aid and Audio Funding (Tammy)
As of Wednesday, March 26th, over 100% of available funds for fiscal year 2013 have been obligated with the Hearing Aids and Audiological Services program. Provider Claim Systems will begin to put children on a wait list and enroll them as funding is available ensuring that we can meet all previously obligated enrollments.

Children who are enrolled or in process of enrollment will receive services as approved. Any outstanding claims, including invoice and insurance information needs to be submitted immediately or as soon as possible after the delivery of the service. If you have questions about children enrolled, billing, etc., please contact Lori Wink at 800-547-6789.
New enrollee’s prioritization:
- children 0-3 years of age in need of hearing aids
- children 4-20 years in need of hearing aids
- chronological order based on the date of receipt of a completed application

Regional Programs Update (Susan)
Charles City will be the site of the first regional program; continued professional development will be offered at this location. No official word on the funding request to support the regional program from the legislature as of yet. Currently, planning committee is moving forward regardless of funding approval/denial from legislature. Professionals in the educational community are responding well to these programs.

Q. Tammy: Have you heard from the parents in the area?
A. Superintendent has heard from the parents. A survey was developed to obtain statewide feedback from the parents to determine their specific needs.

Q. Bob: Charles City is far away from some of the deaf students. Is there a possibility in future to expand these programs so it could be closer to some of the deaf students?
A. Marsha: We had originally selected five sites. We have not decided on the specific sites as a lot of different factors are being considered when choosing these sites including specific needs, distance, community resources (college, technical programs, etc.) Also, lessons learned from the first site will be taken into consideration when selecting additional sites. There was some discussion about why Charles City was selected (numbers of students, infrastructure, partnerships with vocational rehabilitation, colleges, job development opportunities, excitement of partners, etc.)

Q. Is there a website that contains information and updates about the regional programs?
A. Currently, there is no website available. All meeting minutes from the planning committees is posted to the Board of Regents, School for the Deaf and Iowa Educational Services for the Blind and Visually Impaired websites.

National EHDI Conference/Lucinda Nomination
National EHDI Conference will be held on April 14th and 15th in Jacksonville, FL. Tammy and Esha are attending from the Department of Public Health and Caitlin Sapp, University of Iowa audiology student. Lessons learned and individual experiences will be shared at the July meeting.
Tammy and Esha have several presentations they are doing and Caitlin and Tammy have a poster.

**Deaf Capitol Day, Endeavor Magazines, Deaf Coalition of Iowa, New Book**

Bob Vizzini:

1. Deaf Capitol Day flyer was sent out to committee members. Bob and Kathy asked that this be shared with parents, educators and professionals working with deaf and hard of hearing children. Bob stated the Deaf Coalition’s focus at this time is on the education of deaf and hard of hearing children. If an organization or agency wants to have a display table that day, contact Kathy or Bob for assistance.

2. Bob reported that he obtained copies of several issues of Endeavor magazines from the American Society for Deaf Children that Bob is willing to share. Send him a request if interested.

3. Bob reported a new book came out in February, written by Gina Oliva (who is sometimes involved in the national EHDI conference). The title is “Turning the Tide: Making Life Better for Deaf and Hard of Hearing Schoolchildren.” Bob said the book is important as it talks about the challenges for deaf and hard of hearing children who have been mainstreamed in their local schools. Bob said that Gina told him they could offer a discount if multiple books are purchased (20). Contact Bob if you are interested in partnering with him to buy the books. The books will not be available for the Deaf Capitol Day but it could be made available for parents or educators at a later date. To learn more about this book, etc., visit the following website: [http://www.turningthetidemakinglifebetter.com/](http://www.turningthetidemakinglifebetter.com/).

4. Bob reported that nationally there is a push to improve education for deaf and hard of hearing children. He reported many states are unaccountable in their education progress because there is only one state that actually has standardized testing data specifically among deaf/hard of hearing children (NC). CEASD.org (Conference of Educational Administrators for Schools and Programs of the Deaf), and NAD (National Association of the Deaf) have worked together with deaf educators in developing the Alice Cogswell Act. They would like to get this act passed through congress and amend the IDEA and LRE laws. For more information about this act, please visit [http://ceasd.org/child-first/alice-cogswell](http://ceasd.org/child-first/alice-cogswell). Bob stated that for years it has been hard to improve accountability when deaf children are pooled with disabled or handicapped children. The educational needs & accommodations are different. Alice Cogswell Act, like the blind educators plan to have Anne Sullivan Macy Act, will address these children more in their individuality rather than as a group with all disabled children. Bob reports they
have not heard of any Iowa leadership in support of the bill while other Deaf schools in the nation have voiced their support. Bob encouraged members to learn more about the act and support it. Email Bob Vizzini for information on this and the article on the lack of data accountability by states.

5. Bob reported that he currently chairs the Deaf Coalition of Iowa. It is their position that the leadership for Deaf Education in Iowa is not making the necessary efforts to recognize the Alice Cogswell Act. The coalition is also concerned about accountability within the schools, including more experts in deaf education on the committees. Bob reported they have voiced their concerns that deaf people, deaf organizations and education experts of the deaf are not represented as the majority on a number of the planning committees used to determine education for deaf children. The Deaf Coalition of Iowa is in the process of writing to their legislators to express their concerns. If you are interested in receiving a copy of the letter, please contact Bob Vizzini. Additionally, the Deaf Coalition welcomes parents, interpreters, and educators to join their organization and committees.

6. Bob shared his opinion and that of parents of deaf children related to the hiring of a new Superintendent. The new Superintendent will continue to oversee both deaf and blind schools and the regional programs. Bob reported that he has heard deaf people tell of their frustrations and failures as well as parents, interpreters and some special education teachers. They admit many of them are not trained enough for the profession, there is no deaf education training in Iowa to get support, and many of them are short staffed, and the children are suffering because of it. If the New Superintendent is someone, the newspaper quotes from the Board of Regents as being someone who does not need to have deaf or blind teaching experience, we will not see effort to make positive changes.

10:15 – 10:30

**EHDI Transition (Tammy)**

Short-term and Long-term follow up: Child Health Specialty Clinics (CHSC) has been working closely with IDPH to administer Iowa’s EHDI program through funding provided by a federal grant from the Health Resources and Services Administration (HRSA) for many years.

Beginning January 2014, the IDPH EHDI program took over administration of follow up from hospital screening through enrollment in intervention and family support services. This transition also includes the dissemination of risk factor letters to parents and the infant’s primary care provider. All follow up communication regarding screening or diagnostic assessment appointments is
now coming from one of the following persons in the form of a phone call or email: Jinifer Cox (EHDI program Assistant); Esha Steffen (EHDI Follow up Coordinator); or Tammy O’Hollearn (State EHDI Coordinator). CHSC continues to advocate for children with hearing loss through Iowa’s Title V Program for Children and Youth with Special Health Care Needs.

**Staffing:** Additional staff will be hired after the HRSA grant award is received to help with follow up activities, Guide By Your Side referrals, etc.

**Data Analysis:** Tammy and Esha have worked on extensive data analysis at the department over the past couple of years. Data will be shared with the national partners and other states during a presentation at the national EHDI meeting in April 2014. Presentation is titled “Improving Loss to Follow-up rates Among Iowa Babies: Strategies for Success.” The presentation will highlight the various strategies used throughout each phase of follow up and discuss the progress made towards decreasing lost to follow up/documentation rates and in meeting the needs of Iowa children, families and providers over the last three years. The presentation will provide participants with information on how program staff identified issues that contributed to loss to follow up/documentation numbers and then developed strategies to address the issues using a collaborative approach.

**10:30 – 10:45**

**CDC & HRSA Grant Submission Updates (Tammy)**
The competitive application for Iowa was submitted to HRSA mid December 2013 for the next three year cycle (2014-2017). The grant awards were expected to be released at the end of March but the release date has been delayed. Iowa has not yet received word on the amount of the award. The last grant cycle ended on March 31, 2014.

CDC Grant: The annual progress report and application was submitted to the CDC on March 28, 2014. IDPH EHDI is entering the fourth year of a five year project with CDC. The CDC grant cycle is July 1st through June 30th.

**10:45 – 11:00**

**Hearing Loss Symposium (Susan)**
Susan reported that there is no funding available for the hearing loss symposium but she is hoping they can do advocacy training in the fall for parents. She is uncertain at this time if the training will be one or two days.

**11:00 – 11:15**

**Audiology Student Research Projects (Emily/Caitlin)**
Emily Andrews reported that Amy Carlson completed a research project for the EHDI program regarding risk factors for hearing loss using Iowa EHDI’s eSP™
database. A total of 160,761 children’s records were reviewed for children born in Iowa between January 2007 and December 2010. Of those children born, 154,730 infants received a newborn hearing screen. Of those, 272 were identified with congenital permanent hearing loss, 127 of whom had risk factors and 145 of whom did not. The overall prevalence of 1.8 per thousand newborns with congenital hearing loss agrees well with published literature. An additional 92 babies developed permanent hearing loss before 3 years of age with 34 of the children having risk factors and 58 with no risk factors. The report is available if any member has additional interest. Contact Lenore Holte, Lenore-Holte@uiowa.edu or Tammy O’Hollearn, Tammy.OHollearn@idph.iowa.gov.

Caitlin Sapp shared with committee members she will have a poster presentation at the national EHDI meeting in Jacksonville, FL. Poster is titled, “Extending Newborn Hearing Screening to Homebirth Populations in Iowa.” This project was aimed to incorporate homebirth families’ concerns and present the newborn hearing screening as an important decision they can make to prioritize their child’s future as a communicator using language. Caitlin will share information about her project, including information created specifically for home birth families as well as the educational letter mailed to Iowa midwives.

Emily reported there are three other audiology students that are currently working on literature reviews.

11:15 – 11:30 Short-Term Follow Up (Esha)
Esha presented the short-term follow up (STFU) analysis for 2013. 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 and entering results from audiology 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 the key points from the PPT:

- In summary, the EHDI program at the Iowa Department of Public Health followed up on a total of 6160 babies in 2012. This number includes babies that may have been in the NICU for several months, and therefore,
get counted multiple times. The total number of actual babies referred to IDPH requiring follow up is 5043. The breakdown of each category is as follows: Family & Healthcare Provider Follow-up (23%); NICU (51%); Transfers (3%); Out of state (3%), Iowa Health (20%).

**NOTE: Home births are now included in the Family & Healthcare Provider Follow-up.**
- Total babies that continue to be “in-process” are 96.
- Lost to follow up/documentation (Based on STFU only):
  
  \[
  \frac{174}{1399} = 12\% \quad \text{(Preliminary)}
  \]

The overall percentages for lost-to-follow up/documentation were also shared with the committee members. The percentages have decreased significantly over the past four years:

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>2009</td>
<td>60.9%</td>
</tr>
<tr>
<td>2010</td>
<td>55.0%</td>
</tr>
<tr>
<td>2011</td>
<td>36.9%</td>
</tr>
<tr>
<td>2012</td>
<td>28.0%</td>
</tr>
</tbody>
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Some of the strategies EHDI program staff used to reduce follow-up rates included:
- Regular data match with Vital Records to ensure accuracy and completeness of data
- Routine quality assurance checks to maintain high quality of data
- Active follow up on babies who initially miss or refer on their birth screen that have not returned for a follow up hearing screen
- Active follow up on home birth families with a phone number listed in the EHDI database to ensure they are aware of screening locations
- Increased primary care provider involvement to encourage PCPs to emphasize importance of timely follow up at the well-child exams
- Encouraging families to make a decision about screening so children don’t get marked as lost in the database if they have no intention of taking their child back for a re-screen
- Collaboration with Title V agencies to reduce LTF rates

*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.*

11:30 – 12:30 LUNCH
12:30 – 12:45

**GBYS Update (Susan)**

2013 babies:
32 families were contacted by phone, email, or text messaging following diagnosis of permanent hearing loss – mostly cold call – not outside referral
14 families enrolled in GBYS
10 families GBYS was unable to make any direct contact by phone or email, so a letter was sent to the family describing the program.

GBYS Family to Family conference calls were expanded to noon and evening time. Evening calls had much better participation rates with an average of 4 parents calling in. If the conference call or online meeting is offered again in the future, evening time is best.

No contacts for family support are being made for babies born in 2014 or diagnosed in the later months of 2013. Currently there is no Family Support Coordinator and there are no parent guides provided through Iowa EHDI Family Support. Susan reported they are hoping to have the coordinator position filled quickly after grant funding notifications are received. Once the program is up and running again, the program has a goal of September 1 to secure funding for parent guides. Susan has been exploring other options for funding the guides due to the lack of funding within the EHDI grants.

**Marsha:**

**Parent Sign Language:** There is an online parent sign language taught by a deaf instructor being offered. AEAs were asked to notify families of children with hearing loss of the opportunity to learn sign language. Their experience has been better than ICN classes. The curriculum includes information on deaf culture as well as teaching sign language. The course will last about six weeks. Duration of the course may depend on funding. Changes will be made based on the lessons learned and specific needs. Currently, there is no cost for the online course.

*NOTE: Books have been loaned out to the parents as they cost $60 each.*

**Superintendent Search:** Team selected a small number of candidates following an extensive search. There will be two interviews. The first round of interviews will take place in the middle of April. Team comprised of two deaf adults, three parents with children that are deaf/visually blind, special education instructors, etc.

12:45 – 1:15

**Hospital Progress Reports/Tips Survey (Esha)**

Survey findings were shared with the committee members. Esha reported the purpose of the survey was to collect feedback from all the birthing facilities to:
1) determine the effectiveness of quarterly hospital progress reports and weekly EHDI tips; 2) measure their impact on everyday newborn screening practices including documentation and follow-up; and 3) identify specific knowledge gaps that need to be addressed to improve hearing outcomes for children and families of Iowa. The total number of surveys emailed were 79 with the response rate of 48% (n=38). Overall, feedback was mostly positive with some suggestions on the format and frequency of the tips and reports. The EHDI staff have taken these suggestions into consideration and made modifications accordingly.

*Survey findings are available upon request. If you’d like a copy of the slides, please contact Esha Steffen at esha.steffen@idph.iowa.gov.*

1:15 – 1:30

**Data Integration (Tammy/Kim)**

**Title V Pilot Project:**
The EHDI program staff met with Title V program consultants in December of 2013 to explore the feasibility of data sharing methods to communicate children in need of follow up to determine if the child health programs served the same children in need of follow up and if they could assist in scheduling further hearing healthcare appointments. Following the initial meeting, the EHDI program staff completed an analysis of children served by Title V agencies with the greatest number of children lost to follow up from the EHDI program. Upon completion of analysis, the team determined three Title V counties to target for a pilot: Scott, Black Hawk and Taylor. A memo has been developed that will be distributed to the agencies in the near future to explore their interest.

1:45 – 2:45

**Best Practices Manual Work Groups**
Members were divided into two groups: Parents and Audiology (Diagnostic Assessment). Each group was assigned certain chapters from the best practices manual based on their expertise on the subject matter. Some suggestions included:

**Parents:**
- “Explain” instead of “tell” them why hearing screening is important
- Insert bullet points under this topic
- EHDI Brochure…”Review” the EHDI brochure instead
- Clarify dialect of Bosnian Language (languages in eSP™)
- GBYS- Avoid using the word “meet” as it is usually via phone or email
- Insert NCHAM material about talking to parents
Audiology (Diagnostic Assessment) Section:
- Make 1-3-6 goals bolded to make them stand out more.
- Refer to online training available through NCHAM website
- Integrating ongoing best practices
- Do not refer babies to as “it”, replace with he/she
- Take out OAE when referring to OP screen, it could be OAE/AABR, etc.
- Keep NICU or Well-baby nursery sections separate

2:45 – 3:00

Wrap Up/Sharing
Please send agenda items to Tammy O’Hollearn at tammy.ohollearn@idph.iowa.gov.

Meeting dates for 2014 (Location TBD): July 10th; October 2nd