Early Hearing Detection and Intervention Advisory Committee Agenda
Thursday, October 3, 2013
10 – 3:00 p.m.

Location: West Des Moines Public Library, Community Room, 4000 Mills Civic Parkway, West Des Moines, IA

Present: Heather Dirks, Jeff Hoffmann, Marcy Clausen, Valorie Caputo, Sally Nadolsky, Heidi Smith for Jill Avery, Robert Vizzini, Teresa Hobbs, Shannon Sullivan and Kathy Miller

Staff Present: Esha Steffen, Leslie Huber, Susan Rolinger, Emily Andrews and Tammy O'Hollearn

Introductions & Announcements

Hearing Loss Symposium (Emily Andrews) – Applied for a Community Betterment Grant with Prairie Meadows. Sara Patkin, conference planner, is looking for venues in the Ankeny area because the hotel typically used is not available. Emily noted that the Robert Woods Johnson Foundation that funded our conference a year ago said that they liked what we did, but they do not fund initiatives such as a conference over and over. Lenore should hear from Prairie Meadows in January or February. If any EHDI advisory committee members want to be a part of the planning committee, contact Lenore Holt at lenore-holte@uiowa.edu.

Leadership Team (John Cool/Susan Rolinger) – John shared that the team meets monthly. The last few meetings the team outlined the expectations of all the entities involved in regional programming. The team reviewed a draft budget, where the funding might come from, etc. John reported the draft budget shows it would take in excess of $700,000 to fund one of the regional programs. Patrick and John are working with the Department of Education (DE) to review all the possible funding options. Part of the funding will come out of the weighting of students, DE, and funding from the School for the Deaf appropriation. The team anticipates asking the legislature for additional funding. Funding of a regional program in a more populated area may be close to 1.3 million dollars. John reported that the DE is supportive of regional programs to meet the needs of Deaf/HH/Blind/VI students. Final recommendations will be made to the Board of Regents in the next couple of months.

The team narrowed the location for the first regional program to NE Iowa, specifically the Charles City area. The leadership team recommends the pilot of two regional programs; one in a more rural area of the state and another in a more populated area. The next meeting will be held in November.
Language changes will need to be made in the Iowa Code. Those changes will go through the Department of Management and the Legislature following public meetings which are required during that process.

Susan reiterated there are many meetings going on behind the scenes to sort out all the details of planning for regional programming. She shared that the team is trying to ensure the programs are within an hour of a family’s home so access to the programming is rather easy and services will support or enhance the programming already in place. Susan said there is a subcommittee that is working on a survey to go the families in the area where the pilot regional program will be to get a feel for families’ thoughts about this opportunity and at the same time provide education about the goals of the program related to services and supports.

Val Caputo, AEA audiologist, asked for information on the students in their AEA that could possibly be served at this type of regional program. She said there is uncertainty and concern that itinerant services will go away. John responded there is not a clear answer regarding what the regional program may look like or who specifically will be served. He commented the team is looking at all services of deaf and hard of hearing students and working with the programs currently serving those individuals to get a feel for the needs that may be needed. John explained the programs will be added to the continuum of services already available. John and Susan both reiterated referrals to the regional program will happen through the IEP process. Susan commented that some students are served well by the itinerant teacher model and others are not and it is those children that are not getting the services they need that the program will provide additional supports for near home. Susan said that itinerant teachers may be able to focus more on working with their students rather than spending large amounts of time driving around from student to student.

Marcy confirmed with John and Susan that the regional programs will still be a school based model which will allow integrated classes, students the ability to come and go as needed and yet for some students it may be an opportunity provide much more support. Marcy asked about the more involved students that may have severe to profound loss plus additional needs. John commented he is not sure how they will be served at this time. Susan said it is a work in progress. She said that a placement may be a half year placement; not necessarily for the entire year or could be morning or evening and/or may include distance learning. She stated it is hard to anticipate what kids need and who will be interested in participating until the first regional program is up in running. Marcy said they struggle with kids that may just need equipment support or itinerant occasionally. John commented they are looking at providing direct instruction through distance learning. John said the team has support to pursue distance learning opportunities or other creative programming so long as it meets the needs of the students. John said the itinerant teachers at the AEAs have provided great input into the development to the program including possible realizations that must be considered with a regional program.
The goal is for the first program to be up and running in 2014.

**ECHO Training (Emily)** – Emily provided an explanation about the ECHO Training program and its purpose. Emily recently attended their newest training. A condition of her participation in the new training was to provide training to two more early childhood programs in Iowa by February. ECHO surveyed the Early Head Start programs to see who is ready and provided that list to Emily. Tammy shared the names of the current EHS programs screening and reporting to the EHDI program. To learn more about the ECHO program, visit [www.infanthearing.org](http://www.infanthearing.org).

Sally Nadolsky reported that a couple Title V programs (child health programs) had also purchased equipment and have approached her about payment for performing hearing screenings. Sally shared that she will consider paying for the hearing re-screen if there is a need and if there are protocols specifically for a Title V program screening. Tammy and Emily shared that the protocols that the Early Head Start programs follow would be a great start for the children that are a little older and in need of screening and we currently have protocols for re-screens of infants. Tammy will work with the Title V personnel at IDPH to put together protocols and further explore need.

Tammy provided an update about the PAT programs, the webinar she did and content (protocols, reporting, developing a partnership with a community/AEA audiologist, cost, need, etc). Val noted she did get calls from PAT programs in her area following the webinar by Tammy.

**Long Term Follow up (Leslie)**

Leslie explained the difference between the follow up Esha does and the kids she is following. Leslie provided a Power Point (attached) with numbers outlining follow up and their outcomes.

Leslie reported that she is continuing to work with providers to increase the number that automatically include hearing aid data in eSP™. If the information is not in the system, she follows up to obtain that information. Leslie provided an update regarding early intervention referrals for 2012 and the work that is being done to develop a referral form to make the EA referrals more automatic.

Leslie discussed a small test of change she is trying related to sending a fax to primary care providers for children still in need of a diagnostic assessment vs. making a call. She said that faxing offers an alternative method to contacting providers especially if she has already contacted them in the past. She is trying to make the process more automated and timelier, when possible. Leslie received mixed responses so needs to try this a little longer. A few PCPs responded and others did not.

**Family Resource Guide (Leslie)**

Leslie provided an update as to where things are at with updating the Iowa EHDI Parent Resource Guide. She reported they are trying to bullet some of the content so there is more white space and less
words. They are looking at ways to divide the guide into additional sections so parents/providers can
download all sections or just the ones they are most interested in at the time.

Leslie requested more family stories and even ones from parents of recently diagnosed children noting
that stories provide a personal story other families can relate too. She also requested additional pictures.
Send this information directly to Leslie at leslie-huber@uiowa.edu.

A personal family notebook will be added at the end of guide so parents can keep their notes,
paperwork, assessments, etc. The guide will also be translated into Spanish once the English version is
complete.

Leslie provided time for the committee members to review the changes to the guide thus far and provide
additional suggestions.

**HRSA Grant Goal Planning (Tammy)**
Tammy explained that the guidance is due anytime for the HRSA grant which focuses on follow up. She
noted the guidance this application will also have a strong focus on the inclusion of quality improvement
activities. The committee members were divided into small groups. She asked committee members the
following questions:

1) **What do you see as strengths of the program?**
   - Adverse advisory committee
   - EHDI website
   - eSP™ improvements
   - Family Resource Guide
   - Good outreach
   - Improved data collection
   - Information sharing has increased timely follow up
   - Decreased number of children lost to follow up/lost to documentation
   - Nationally recognized leaders in Iowa’s EHDI program
   - Iowa EHDI personnel have a good understanding of other state EHDI programs and use
     them to avoid reinventing the wheeel

2) **What do you see as areas in need of improvement?**
   - Do the right people know about EHDI?
   - Clearly define roles of the EHDI Advisory Committee Members
   - Increase communication so that parents know in advance birth about newborn hearing
     screening and the importance of follow up
   - Continue to improve follow up/referral increasing timeliness and parents that follow
     through
• Review follow-up for babies with risk factors to ensure they are returning for recommended follow up screening

3) What strategies could the program use to improve the areas identified as needs?

• Add a section to the website that includes Deaf role models as well as hard of hearing role models so parents know what the future holds (e.g. college, employment, etc)
• Add video to the EHDI website of communication options
• Further distribution of the Loss & Found video
• Public education (e.g. Facebook page, publicize May Speech and Hearing Month, explore use of text message use for communication)
• Further educate PCPs & parent regarding guidelines for follow up for assessments and risk factors
• Explore whether hearing screening and the national 1-3-6 goals are included on the national “Text for Baby” effort
• Develop a flow chart and script for a physician to use regarding the importance of follow up at the child’s first well child visit
• Explore other states family resource guides to see if there are other resources that should be added to the current family resource guide
• Encourage advisory committee members to advocate and reach out to their peers about 1-3-6 and importance of decreasing the number of children lost to follow up/lost to documentation
• Increase the number of diagnostic providers for infants

1-3-6 Goals (Esha/Tammy) - Check with Esha to see if she has a copy of the visual documents

Esha and Tammy reviewed how Iowa is doing in meeting the 1-3-6 goals. See attached for copy of the graphic that outlines lost throughout screening, diagnosis and enrollment into EI.

GBYS Update (Susan)

Susan provided the following update regarding referrals and enrollments to GYBS for 2012 and 2013 for child with a permanent hearing loss.

2012 babies: 58
  33 contacted directly
    22 enrolled in GBYS
    8 requested additional material be sent and to be contacted at a later date
  25 unable to contact, letter with information about the program sent

2013 babies: 32 as of October 1st
  26 contacted directly
    12 enrolled in GBYS
    10 requested additional material be sent and to be contacted at a later date
GBYS continues to host family to family conference calls on the third Wednesday of each month with guest speakers. Attendance has not been great, but the last call had the greatest number of parents on it to date. EHDI has reached out to the AEAs and family support to advertise these calls.

GBYS and Iowa Hands & Voices will be hosting families at pumpkin farms across the state. This is the ninth year hosting the event. Look for a story about this in the winter newsletter! Susan reports continued struggles with serving families due to staff cuts, but is pleased with the support offered in light of budget constraints.

**Hearing Aids and Audiological Services Funding (Tammy)**

Tammy encouraged committee members to review the recently posted issue brief on the EHDI website, [http://www.idph.state.ia.us/iaehdi/common/pdf/audiological_2013brief.pdf](http://www.idph.state.ia.us/iaehdi/common/pdf/audiological_2013brief.pdf). The brief summarizes the use of the Hearing Aid and Audiological Services program funding for 2012-2013. Tammy let committee members know that the funding was included in the child health appropriation at the end of the 2013 legislative session so the funding became available July 1st.

**Wrap Up/Sharing**

Committee agreed to cancel the January meeting due to timing and cost. Agreed to the program providing committee members with a summary of activities’ completed by program and any updates regarding data.

*Meeting dates for 2014 – April 3, July 10 and October 2*
Slide 1

CHSC Long Term Follow-up (LTF) Results for 2012

Leslie Huber
University of Iowa, Child Health Specialty Clinics (CHSC)

Slide 2

In Process
- Identify babies that DNP birth and outpatient screen,
  - Need a diagnostic assessment
    No later than 3 months of age
  - If transient or not yet determined loss:
    - Need to get them to a hearing diagnosis
      WNL or Perm HL

Slide 3

Permanent Hearing Loss
- Babies diagnosed with permanent HL
  - Confirm referral/enrolled EI/EA (no later than 6 months old)
  - If family chooses hearing aids/CIs:
    - Date of fitting
    - Models should be documented in OZ (not required by law)
Slide 4

### Long Term Follow Up for Children Born in 2012

<table>
<thead>
<tr>
<th>Status</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete - Diagnosed</td>
<td>570</td>
<td>63.3%</td>
</tr>
<tr>
<td>Final Process</td>
<td>13</td>
<td>1.5%</td>
</tr>
<tr>
<td>Referred</td>
<td>434</td>
<td>51.1%</td>
</tr>
<tr>
<td>Biateral Loss</td>
<td>11</td>
<td>1.3%</td>
</tr>
<tr>
<td>Unilateral Loss</td>
<td>14</td>
<td>1.7%</td>
</tr>
<tr>
<td>UNIV H-Loss</td>
<td>2</td>
<td>0.2%</td>
</tr>
<tr>
<td>No Response</td>
<td>1</td>
<td>0.1%</td>
</tr>
<tr>
<td>Refused</td>
<td>2</td>
<td>0.2%</td>
</tr>
<tr>
<td>Lost to Contact</td>
<td>41</td>
<td>4.9%</td>
</tr>
<tr>
<td>Moved out of State</td>
<td>16</td>
<td>1.9%</td>
</tr>
<tr>
<td>Deceased</td>
<td>1</td>
<td>0.1%</td>
</tr>
</tbody>
</table>

Slide 5

### 21% In Process: Require hearing diagnosis

<table>
<thead>
<tr>
<th>Status</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received Audiology Assessment</td>
<td>73</td>
<td>93.6%</td>
</tr>
<tr>
<td>No Audiology Assessment</td>
<td>5</td>
<td>6.4%</td>
</tr>
<tr>
<td>Awaiting Results from out of state provider</td>
<td>3</td>
<td>3.7%</td>
</tr>
<tr>
<td>Assessment Scheduled</td>
<td>3</td>
<td>3.7%</td>
</tr>
</tbody>
</table>

Slide 6

### 321 Babies have received at least one Audiology Assessment

<table>
<thead>
<tr>
<th>Status</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal Hearing</td>
<td>105</td>
<td>32.6%</td>
</tr>
<tr>
<td>Biateral Loss</td>
<td>46</td>
<td>14.3%</td>
</tr>
<tr>
<td>Unilateral Loss</td>
<td>12</td>
<td>3.7%</td>
</tr>
<tr>
<td>Transient Loss</td>
<td>23</td>
<td>7.2%</td>
</tr>
<tr>
<td>Lost or Moved before getting an Audiology Assessment</td>
<td>30</td>
<td>9.3%</td>
</tr>
</tbody>
</table>
Slide 7

Hearing Aid Data Complete in eSP/OZ for Babies PHL

- Hearing Aid Data Listed
- No Hearing Aid Data

Slide 8

Early ACCESS #s for 2012

- Enrollment of Referred
- Referral
- Not Yet Enrolled
- Enrolled
- Decline EA

Slide 9

QI Project: Fax vs. Phone

- Faxing offers an alternative method to contact providers
- Helps automate the follow up process
  - Time saving compared to phone calls
  - Faxes are not listed in the database
  - Do Providers prefer faxing to phone calls
- Which method changes providers' practices more rapidly
QI Project: Fax vs. Phone

- Faxing offers an alternative method to contact providers
- Helps automate the follow up process

? Time saving (not listed in the database)
? Do Providers prefer faxing to Phone calls

Which method changes providers practices more rapidly?

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QI Project: Fax vs. Phone Calls

Responded to Fax

- Yes
- No

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Responses to Fax

- PCP Encouraged Family to Follow up
- Family unresponsive
- Referral to Otolaryngologist
- New Results: Re-evaluation needed
- New Results: completed results
- New PCP Added
- No new Information from PCP response
QI Project: Fax vs. Phone Calls

Number of days for faxed response

- Same day response
- Next day response
- Within one week
- Within two weeks
- No response

Number of days for faxed response
2010 EHDI Data Analysis (1-3-6)

2010 Total Births 38572

Missed 277

Received Screen 242
(178 By 1 mo. of age; skipped to AA (1))

Referred 16 (12 by 3 mo.)

Passed Both 226

Hearing Loss 2 (Bi/Uni)

Lost Contact/Deceased/in process (10/1/3)

Refused 1

Delayed Onset 1

Passed both 35445

Screened (Pass, Refer) 37805
(37274 by 1 mo. of age)

Referred 2360

Outpatient Referred 303 (124 by 3 mos. of age)

Outpatient Passed 1734 (1575 by 3 mos. of age)

Skipped straight to audiological assessment 51 (19 by 3 mos. of age)

Hearing Loss (Bi/Uni) 10/2

Normal Hearing/Transient Conductive 23/8

In process 8

Hearing Loss (46/15) (Bi/Uni)

Refused/Lost Contact/Deceased/MOS/In Process 3/84/0/8/36

Normal Hearing/Transient Conductive 95/16

Enrolled in EI 29 (By 6 months of age)

Refused/Unknown 27

Enrolled in EI intervention 29 (By 6 months of age)

Refused/No info. available 2

By 6 months of age

Delayed Onset 6

Delayed Onset

Passed Both
Total infants screened by 1 mo. of age =

\[ \frac{37452 \text{(recd. screen + screened)}}{38081 \text{(missed + screened)}} = 98.3\% \]

Total infants diagnosed by 3 mos. of age =

\[ \frac{1730}{2376} = 72.8\% \]

Total infants enrolled in early intervention within 6 mo. of age

\[ 8 + 29 = 37/75 = 50\% \]

Refused EI/Unknown

\[ 1 + 2 + 27 = 30/75 = 40\% \]

Total infants enrolled in EI beyond 6 mo. of age

\[ 1 + 4 + 7 = 12/75 = 16\% \]

Total infants enrolled in EI

\[ 12 + 37 = 49/75 = 65\% \]

*****Numbers off by 5 kids. Not sure where to subtract the number from*****
2011 EHDI Data Analysis (1-3-6)

2011
Total Births
38039

Missed
153

Received Screen
115
(67 By 1 month of age; skipped to AA (9))

Referred
8 (4 by 3 mos. of age)

Passed Both
107

Delayed Onset
6

Passed both
35080

Screened (Pass, Refer)
37353
(36836 by 1 month of age)

Delayed Onset
6

Referred
2273

Outpatient Referred
238 (187 by 3 mos. of age)

Hearing Loss
(Bi/Uni) 8/5

Normal Hearing/Transient Conductive
46/10

Enrolled in EI
17 (out of 37)
By 6 months of age

Refused
1 (out of 13)

Passed both
35080

Skipped straight to audiological assessment
87 (57 by 3 mos. of age)

Outpatient Passed
1718 (1573 by 3 mos. of age)

Hearing Loss
(Bi/Uni)

29/8

Normal Hearing/Transient Conductive

Enrolled in EI
17 (out of 37)
By 6 months of age

Deceased/MOS/Refused/No info.
available
7

Normal Hearing
3

In process
1

Lost Contact
4

Hearing Loss (Bi/Uni)
8/5

Normal Hearing/Transient Conductive
46/10

Refused
1 (out of 13)

Passed Both
107

Delayed Onset
6

Enrolled in EI
8 (out of 13)
By 6 months of age

Outpatient Refered
238 (187 by 3 mos. of age)
Total infants screened by 1 mo. of age =

36903 (recd. screen + screened) / 37506 (missed + screened) = 98.4%

Total infants diagnosed by 3 mos. of age =

1751/2281 = 76.7%

Total infants enrolled in early intervention within 6 mo. of age

8 + 17 = 25/50 = 50%

Refused EI/Unknown

1 + 7 = 8/50 = 16%

Total infants enrolled in EI beyond 6 mo. of age

4 + 13 = 17/50 = 34%

Total infants enrolled in EI

25 + 17 = 42/50 = 84%