

The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

April 13, 2017

Meeting Minutes

1:00 pm – 3:56 pm

Ashland Public Library

Attending:

Members

Nina Baker
Laura Beshaler
Katie Brennan
Jenny Corum
Rhonda Fleischer
Nancy Hengelfelt
Brenda Hoover
Shelli Janning
Kim-Jae Kang
Rick Kang
Kelly Rausch
Stacie Ray

Guests

Nicole Pond, UNL Student, HearU
Kelly Malcom, UNL Student, HearU

Staff

Jim Beavers
MeLissa Butler
Brenda Coufal
Marietta Mathis
Gabby Tachenko

Liaisons

Cole Johnson
Joan Luebbers
Laurie Miller

Teleconference

Sara Peterson

Interpreters

Kelly Brakenhoff
Jamy Elker

Newborn Screening Staff

Krystal Baumert
Julie Luedtke

Meeting start time – The meeting was called to order by Committee Vice Chair, Kim-Jae Kang, at 1:00 pm.

Open Meeting Act – Presented at the beginning of Advisory Committee Meeting by Kim-Jae Kang.

I. Welcome and Introductions

Kim-Jae Kang, Vice Chair for the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program Advisory Committee, welcomed all Committee members, staff, and guests.

II. Review of Agenda

There were no changes to the agenda.

III. Review of Minutes

The Meeting Minutes from the December 8, 2016 NE-EHDI Program Advisory Committee meeting were distributed via e-mail prior to the meeting. A motion to approve the minutes, as published, was made by Kelly Rausch, seconded by Brenda Hoover, and unanimously approved by the Committee members.

IV. Presentation – Congenital CMV Infection

Dr. Richard Kang, Director of the Ear, Nose & Throat Institute and the Cochlear Implant Center at Boys Town National Research Hospital presented information on Congenital CMV Infection.

Rick pointed out that many people are aware of Zika virus and a lot of funding has been put toward education and prevention. However, CMV is more common and the effects are more severe than Zika. Awareness and education is needed about how CMV transmission occurs, how to prevent it, and how to treat it. A 2012 survey

of 4,184 participants showed that only 7% of men and 13% of women had even heard of CMV, proving that a very small number of people are aware of CMV.

Rick pointed out that the most common side effect of Congenital CMV Infection in newborns and infants is hearing loss. CMV is the leading non-genetic cause of permanent sensorineural hearing loss (SNHL), affecting six to seven per thousand live births. Rick presented statistics about the disease burden of CMV in the US and statistics related to the epidemiology of CMV obtained from various studies.

Rick went on to discuss different types of interventions that can be done for women of childbearing age at various stages; from preconception, throughout pregnancy, and postnatal detection and treatment. Since there is no commercially licensed vaccine available for CMV at this time, education about prevention is critical in stopping the spread of CMV. The CDC has produced educational materials detailing simple and effective measures that can be taken to prevent the spread of CMV. A summary of CMV transmission was discussed, detailing peak times for viral shedding.

Rick discussed the various methods for diagnosing fetal CMV. In utero test methods include ultrasound and amniocentesis. After birth, testing methods include urine sample, saliva swab, and blood testing. The sensitivity and specificity of each type of test was discussed.

Once CMV is identified, anti-viral drugs can be administered. Rick cautioned that the CDC feels the effectiveness of anti-viral therapy is still unknown. However, some studies have shown antiviral therapy to be effective against lessening the effects of CMV. A study of Ganciclovir as antiviral therapy included a cohort of 42 symptomatic infants. Those who received the antiviral therapy were significantly less likely to experience worsening in hearing. Two thirds of the infants treated had significant neutropenia during the therapy. The study also showed that in the short term, there was no significant difference between those who received treatment for six months vs. those who receive treatment for six weeks. However, those who received the six month course did appear to have improved hearing and developmental outcomes in the long term, although the results were modest. The study went on to show the outcomes of those children when evaluated at various milestones.

Rick also discussed the timing of interventions and the challenges of testing and treatment. Overall, the findings show that prevention is by far the best and most effective method for stopping the effects of CMV. The second best method is screening and early identification so the symptoms can be treated and the effects lessened. At this time, universal screening likely will not happen, so the second best option would be to screen babies for CMV when they do not pass the newborn hearing screening.

In conclusion, Rick recommended that women of child bearing age should be aware of CMV, take precautions, and work to raise awareness of CMV with other expectant moms.

Julie Luedtke asked for clarification on the study showing the Dried Blood Spot (DBS) is only about 34.4% sensitive to CMV. Was the method used a genetic test, comparable to SoundGene Panel? Is there potential for sequencing to help with accuracy of blood test? Rick stated that he was not sure if sequencing would be the answer, adding that some still think the sensitivity of testing done on the DBS is better than the study showed. Rick added that saliva swab is still a better and easier method of testing.

Nina Baker commented that at oral health meetings she has attended, research has been presented that shows dental caries are often caused by saliva transmission from mom to baby. Nina went on to suggest that public health awareness efforts could be combined for CMV and dental health to help expectant mothers and new parents understand why saliva transmission between adults and baby should be avoided. Rick said that teaming up with the dental associations could be an idea.

Kelly Rausch asked how aware OB's and pediatricians are of that statistics and prevalence of CMV, adding that these professionals seem like the best people to educate expectant mothers. Rick stated that, unfortunately

many in these groups do not have as much information as they should, because they feel like CMV is extremely rare. Rick has tried to reach out to OB groups, and they are just not interested. The best way to get information out there is to educate moms, because they can pressure others for information, and they are willing to listen since they want what is best for their baby.

Rick also presented information on a new service offered through Boystown called The Comprehensive Hearing Clinic. Currently, Boystown offers a neurosensory clinic where newly identified children can come to see audiologists, genetic counselors, ophthalmologists and ENT's. However, regardless of the etiology of the hearing loss, identified children need other services like early intervention, speech therapy, family support, etc. So, Boystown is expanding the clinic to be more comprehensive and provide the full scope of services.

Brenda C. asked when the new clinic will start, and how often it will be offered. Rick stated they plan to start seeing patients in July 2017, and will start offering the clinic twice a month to gauge the demand. From there, they will determine if they need to offer the clinic more frequently.

Kim-Jae recommended that the EHDI program receive a copy of the brochure for the parent resource guide. Stacie asked that all audiologists receive information on the clinic.

v. HearU/Hearing Aid Bank Update, HearU International

Nicole Pond, UNL Graduate Student and HearU Graduate Assistant, presented the HearU statistics for January 1, 2017 to the April 3, 2017, as detailed in the handout.

Nicole also stated that the Resound Hearing Aids are now available through HearU. Ten hearing aids have been purchased in a variety of models and colors, and are available to eligible candidates.

Nicole also informed the committee that the HearU 5k Fun Run will take place on April 23rd, 2017.

Stacie Ray thanked Nicole for all she has done for all the hearing aid banks at UNL in her two years as the Staff Graduate student. Stacie stated if she had a daughter, she would want her to be just like Nicole, adding that Nicole will be an amazing audiologist and an amazing mother. Stacie expressed her well wishes for Nicole as she moves on to her externship and begins a new chapter in her life as a mother.

Stacie introduced the new grad student, Kelly Malcom. She has already been training with Nicole and will take over once Nicole moves on to her externship.

The committee expressed their thanks to Nicole for her exceptional service to HearU, and welcomed Kelly.

IV. HRSA & CDC Grant Update

Brenda Coufal, NE-EHDI Program Manager updated the committee on the status of the HRSA and CDC grants, as detailed in the handouts.

NE-EHDI received 57.53% of the \$250,000 HRSA funding April 1, 2017. The remainder of the funding will be determined based on the outcome of the continuing resolution that will be decided by the federal government on or before April 28, 2017.

One of the major changes in the new HRSA grant is the requirement that 25% of the funding be allocated to family support organizations. In order to fulfill this requirement, NE-EHDI is distributing the funding to four different areas:

- Guide By Your Side with Hands & Voices

- Shelli Janning will be assisting the EHDI program with follow-up and outreach to parents, PCP's, ENT's and Audiologists. The contract allows for an estimated 16 hours per week to the program.
 - Kiowa Rogers will be assisting the EDHI program with follow-up and outreach to Spanish Speaking families. She has obligated an estimated 4 hours per month to the program.
- Trainings for empowering family leadership and assisting with care coordination plans through the patient/family-centered medical home model. NE-EHDI plans to work with LEND and PTI-NE for trainings during the three year grant cycle.
- Parent workshops
 - Currently there is not funding for the October Roots and Wings Parent Weekend. Cathy Carotta is still searching for funding. If Roots and Wings does not happen, EHDI is looking into a parent workshop through the Care project, which is a National organization that hosts parent workshops similar to Roots and Wings.
- HearU funding for the graduate assistant position and hearing aids

Brenda added that EHDI also wants to collaborate with trainings for families about Deaf Culture and ASL so families are aware of all available resources.

Due to reduced funding, the Advisory Committee Meetings were cut down from four to two per year, and the meetings will now be held in a free meeting space. Brenda asked for feedback from the committee about the new meeting location. The committee and guests agreed that the meeting room at the Ashland Public Library was very nice, and the location was still convenient for both Lincoln and Omaha attendees.

Brenda also asked the committee for feedback on the noon meal provided for the meeting, adding that EHDI would like to continue to provide lunch for our advisory members, as we appreciate that our members and guests are volunteering their time to attend the meeting. Rhonda Fleischer stated that she didn't feel it was necessary for EHDI to provide lunch given the current funding situation. Many agreed with Rhonda, stating that they can get lunch prior to the meeting. Kim-Jae recommended that EHDI poll the committee regarding whether or not to continue serving lunch.

Brenda asked for feedback regarding if 12:00 pm or 1:00 pm is a better start time for the meeting, and if the length of the meeting is still acceptable since we are only meeting twice a year. Brenda Hoover stated she'd rather meet from 12:00-4:00 and be able to leave an hour earlier. Rick stated noon would be difficult with his surgery schedule at Boystown. MeLissa recommended that EHDI send out a Doodle poll for the meeting start time, length of meeting, and lunch option. We will implement the preference of the majority of our members.

At the December 8, 2016 meeting, Brenda asked for ideas from the committee for feedback on presentation ideas, improvements to the meeting format, or other ideas to improve the committee. Brenda shared some feedback she received.

- Suggestions for presentations:
 - EDN and GBYS - regarding how new parents are informed of EDN, referral & verification
 - Jeff Simmons from Boystown - information on auditory neuropathy
 - GBYS – how they approach working with families
 - Kelly Rausch offered to give a presentation from a parent perspective

Other suggestions for improving the meeting included:

- Making sure the microphones have batteries and that everyone uses the microphones

Regarding what works well during the meetings, feedback included:

- Love having the program data presented to the group
- Glad we have name tags

Due to the feedback, Brenda C. has decided to move the data presentation earlier on the agenda to give the topic a higher priority.

Brenda C. stated that she will email the suggestion form to the committee again to give people another opportunity to provide feedback.

Brenda C. presented information on the CDC three year grant, as detailed in the handouts. She highlighted the five grant strategies, and emphasized that the CDC funding goal is to improve the data for timely diagnostic testing and early intervention services to early identify D/HH to help address potential developmental delays. Brenda C. asked the committee for ideas on ways to disseminate data that would help other programs.

Many ideas were discussed, with the main focus on educational outreach to ENT's and Audiologists, stressing the importance of timely appointments, timely reporting, and timely referrals to early intervention. Items discussed included:

- Rick Kang stated he presents information to the medical students at Creighton annually, and this could be an opportunity to share the data and why timely services are important.
- The committee also discussed the possibility of conducting site visits with Audiologists and ENT's. Many agreed that due to the number of audiologists and ENT's, it would be difficult to visit everyone in person. It was suggested to review the audiologists and ENT's who need more information and schedule visits with those few.
- The idea of doing an email blast was discussed, however, many agreed that emails are often ignored or deleted without being read thoroughly.
- MeLissa Butler asked if there are any newsletters that go out to Audiologists and ENT's where we could publish an article. The committee recommended the NSHLA newsletter.
- The committee discussed the idea of NE-EHDI hosting a state EHDI meeting to share data and information with ENT's and Audiologists. Many members did not think the event would be well attended by those we are trying to reach. Those who would attend are already involved and informed. Also, EHDI would probably not have funding to host the meeting. Stacie Ray added that the State Audiology conference is not well attended because there are many online hours available for CEU's.
- Brenda Hoover stated that we need to identify those who are not meeting benchmarks, and then schedule individual meetings. MeLissa Butler recommended that EDHI complete data analysis to identify audiologists and ENT's who need to be contacted. From experience, there's probably around ten who could benefit from an EHDI site visit. In addition, EHDI needs to include a peer, either an ENT or Audiologist for the site visit, as the information will likely be better received from a peer rather than a state agency. Jim stated he will analyze the data and EHDI will develop a list of audiologists and ENT's who would benefit from a site visit.

v. ASTra Training

Shelli Janning, Guide By Your Side Program Coordinator presented information on Hands & Voices Intro to Advocacy and Support (ASTra) training, as detailed in the handouts. Shelli emphasized that ASTra advocates are not lawyers, they are just lay advocates who are committed to the Hands & Voices philosophy and principals. The goal of ASTra is to support and assist parents at whatever level they are at and help them become more engaged and involved in the IEP process. When parents become engaged and fully participate in their child's IEP process, this improves the dynamics of the meetings.

Shelli shared that her 10-year-old daughter, Brooke created a PowerPoint by herself for her IEP meeting, and the entire team was extremely interested in her input. The process empowered Brooke to be a self-advocate. Shelli was very proud as a mom and a Parent Guide.

Shelli also discussed the three levels of the Program Structure for ASTra training:

- Basic Training is intended for any individual that seeks the opportunity to increase their knowledge and skills to advocate for their own child, and/or students they work with.
- ASTra Advocate Training is intended for those individuals who are hired as a Hands & Voices Parent Guide or an ASTra Advocate. This level is for those individuals within Hands & Voices who seek to advocate for families as an official representative of their Chapter or Guide By Your Side Program.
- ASTra Train the Trainer is intended for those individuals within the organization who seek to train other parents and/or professionals in Level one and two required trainings as an official representative of Hands & Voices Headquarters.

Overall, Shelli is very excited about the ASTra training, and hopes to bring a training event to Nebraska in the near future.

vi. NE-EHDI Statistics and Lost to Follow-up Information

Jim Beavers reviewed the handout titled *2014 Birth Cohort Caseload* for Nebraska that was given to EHDI Coordinators by the CDC at the EHDI annual meeting.

Rhonda asked for clarification on the section on Early Intervention, and asked why six children did not qualify for Part C according to the chart. Jim stated there are a number of possibilities, but the most common reason is that they reside out of state.

Rick asked for clarification on the five cases in the Diagnostic Evaluation category who are still in process. This concerns him, because those are the types of cases he sees two to three years down the road where a child is just starting services that they should have received years ago. Jim emphasized that this data was from 2014, and this report was a point in time snapshot of the activities. He will research those cases to date and let Rick know if any of the 2014 cases are still in process.

Jim also reviewed the handout titled *Jan-Dec 2016 DOB NE-EHDI Status Report*.

Rick asked the same question about the 88 babies listed as "In Process" on the report. Jim stated that this is 2016 data, so some could still be in the NICU or have persistent middle ear issues that are delaying confirmatory testing. Again, this is a point in time report, so these numbers likely will have changed. He will look into the number still in process for 2016 and let Rick know the reasons they are still in process, and if any further action needs to be taken on any of these cases.

VII. Revision of Advisory Committee Charter Update

MeLissa Butler informed the committee that the charter has been updated to reflect the changes agreed upon by the committee at the December 8, 2016 Advisory Meeting. A copy of the charter with the revisions was included in the handout packet.

VIII. NE-EHDI Procedures for EDN Referrals Update

Brenda Coufal informed the committee about updates to the referral to EDN protocols that were the result of a meeting that took place between EHDI and EDN in January, 2017. This information can be found in the handouts.

XI. Funding For Parent Resource Guides and Online Update

MeLissa Butler informed the committee that due to information discussed at the January, 2017 meeting with EDN, EDN will now fund the Parent Resource Guides (PRG) for NE-EHDI. EDN can cover these costs since they are required to provide parents with educational materials, and babies Diagnosed with permanent SNHL are within the scope of EDN's responsibility

- Hard copies of the PRG will continue to be available in English and Spanish, in addition to the online version.
- The hard copy PRG continues to be reviewed and revised to make it less overwhelming for parents.
- We are continuing to work on improving the online version of the PRG.
- All DHHS websites will be migrated to a mobile friendly format in the future, which will make the online PRG much more user friendly.

MeLissa also shared with the committee that EHDI finally has photos of Nebraska Kids with HA's to use on our website and in our print materials, including the parent resource guide. Photos were donated by Jordan Sochor Photography. MeLissa also stated that a big thanks goes out to Kendall Sims for coordinating this effort.

XII. Learning Communities Updated

MeLissa Butler updated the committee on the current Learning Communities which are required by the HRSA grant.

Hospital Training Task Force:

- Planning to resume with the new three year grant cycle when time permits.
- Shelli Janning has agreed to offer a parent's perspective as part of the training program that will be developed and presented to hospitals.

Western NE Learning Community:

- Brenda & MeLissa met with the NE Audiology Board.
- The Nebraska State Audiology Board does not currently have a position statement on tele-audiology.
- They will decide on an appropriate position statement.
 - The board will look at statements from ASHA, AAA and state boards regarding Teleaudiology.
 - They will also review information from the education level and the state organization level for recommendations.
 - The next board meeting is in the fall of 2017.
- The board had concerns over the use of LPN's as the Remote End Technician (RET)

- MeLissa stated that the idea of using an LPN as the RET was based on recommendations from the VA
- The Board stated LPN's cannot be supervised by Audiologists, their orders need to come from an MD or RN
- The Board recommended that EHDI contact Nebraska Health Licensing for more details regarding scope of practice and regulations for LPN's
- NE-EHDI will provide the job description for the LPN/RET to the Nursing Board and the Audiology Board
- NE-EHDI is still working on finding a job description for the RET
- The proposed pilot site has ENT's & RN's on staff who could supervise the LPN
 - Ryan Massey confirmed the Western Hearing Clinic is still interested in being the pilot site
- Next Steps
 - Have the Nebraska State Audiology Board review the work plan
 - The Nebraska State Audiology Board will decide on an appropriate position statement
 - NE-EHDI will provide the job description for the RET to the Nurse Licensing Program

Julie stated University of Arkansas may have a job description for a RET that we could use. She will send the information to MeLissa after the meeting.

XIII. Hospital Site Visits Update

Brenda Coufal updated the committee about hospital site visits, as required by the HRSA grant. NE-EHDI was able to conduct four site visits before the prior HRSA grant funding cycle ended March 31, 2017. Hospital site visits will continue to take place, with the goal of visiting each birth hospital in Nebraska every three years.

XIV. Nebraska Award Nominations at EHDI Annual Meeting

Brenda Coufal informed the committee that Shelli Janning was nominated for a Parent Leadership award at the EHDI Annual Meeting in Atlanta in February, 2017.

The NE-EHDI website was also nominated for website of the year, and ranked in the top five of the websites nominated.

XV. EHDI Annual Meeting Presentations

Shelli Janning talked about a session she attended which discussed about divorce rates among parents of a child with special needs. Based on her own experience, she really feels it's important to support fathers because they play an important role, and more resources are needed to help guide fathers through the process.

Kim-Jae commented that when she ran support groups in Ohio, she found that it's not just dads who want to be involved, but also grandparents. Her support groups featured couples talking about how they cope. Discussing their thoughts and feelings in an open and safe environment helped both moms and dads. Other neglected groups are teenagers and siblings. Rhonda commented that at Roots & Wings, special sessions for fathers and siblings are offered, and those sessions have received positive feedback. Shelli agreed with Kim-Jae about the importance of support for grandparents, adding that when her daughter's hearing changed recently, it was really hard for her to decide if she should tell her mother, because she struggles to deal with her granddaughter's hearing status.

Rhonda stated Sara Peterson had to leave, but asked her to relay some of her comments about the meeting to the committee.

Sara stated that the overall tone of the EHDI meeting this year was very different. There was a lot of focus on making sure that parents and EI providers understand that they don't have to choose between oral and sign. The more exposure to all language in the critical early years, the better. The focus of the plenary and breakout sessions seemed to be less medically focused, and more intervention focused. Sara also stated that if anyone wants to access her notes from the meeting, they are in a Google folder online and she can share the link upon request.

Rhonda also stated that a link to the PowerPoint presentations for all presentations from the EHDI annual meeting is available online, along with the transcript of the entire session. She asked for the link to be included in the meeting minutes.

Link to meeting agenda and presentations:

- <http://ehdimeeting.org/Schedule/grid.cfm>
- Click on the presentation to see the PowerPoint if available and the transcript of the session.

Rhonda stated that she enjoyed the presentations on literacy. She was also very impressed with the amount of focus on social and emotional development. In her experience, it used to be that social and emotional development was only talked about when the child became high school age. She's glad people are starting to recognize the importance of those developmental pieces earlier.

She also appreciated the sign language illustration Dr. Robert Nutt used to illustrate his feelings about being "on the fence" between the hearing and deaf world, adding that it hurts.

Rick asked for clarification on the information presented about combining oral language and sign language in early childhood. He added that in past years there has been a lot of pressure from the Deaf community to push ASL on families. Rhonda responded that it felt more balanced and less controversial, and there was less pressure on parents to think that "kids won't speak if you sign too, kids won't sign if you speak too." There was a more balanced message presented on just letting kids take whatever exposure to language you can give them. Shelli added that parents feel guilty enough through the process, and often doubt if they're making the right choices for their child. Being made to feel like if they don't sign they're not doing a good job is a lot of pressure for a parent. On top of that, parents often feel pressure to make a decision right now and feel like they can't change their minds later.

Stacie added that self-selection is so important for parents to understand. Sign vs. oral is not a decision parents have to make, they're options that the kids need to learn are available. Kids will self-select at older ages, often in their teens and early 20's when they're more self-aware and comfortable with what they really want. She gave the example of her son, who has worn hearing aids and can function as a hearing person, but he selected sign language. He chose to date a 5th generation Deaf woman, and prefers the Deaf community for himself.

Katie Brennan added that it's hard for some parents when their deaf educators or early interventionists don't have experience guiding a family through the self-selection process. It's important to help the professionals know how to help guide families.

XVI. Other

Brenda Coufal stated that the date for the fall meeting was scheduled for Thursday October 12th, however, some members have stated that this date will not work for them. Brenda asked if another Thursday in October would work better. Julie stated that the Newborn Screening Advisory Committee was already scheduled for October 26th in this meeting room, so the room would not be available. The committee agreed that either

October 5th or October 19th would work better for everyone in attendance. The date of October 19th was selected, and if anything changed MeLissa would let the committee know.

Brenda also informed the committee that she was contacted by Sarpy County Headstart, and they are looking for an audiologist to be a member of their Advisory Committee. The committee meets three times a year for about one hour. They discuss the Headstart Program and other community activities. There are no requirements for the audiologist to join, they just are looking for stakeholders to bring ideas to the table. If anyone is interested in volunteering, they can contact Brenda for more information.

XVII. Adjourn

A motion to adjourn the meeting was made by Rick Kang and seconded by Katie Brennan. The meeting was adjourned at 3:56 pm.

Next Meeting:

- November 16, 2017

Respectfully submitted by MeLissa Butler, Community Health Educator Senior