

**The Nebraska Early Hearing Detection and Intervention Program**

Advisory Committee Meeting

May 3, 2018

Meeting Minutes

12:02 pm – 4:02 pm

**Nebraska Children's Home Society**

Attending:

**Members**

Nina Baker  
Laura Beshaler  
Jenny Corum  
Linsay Darnall Jr.  
Nancy Hengelfelt  
Kristin Jolkowski  
Kim-Jae Kang  
Ashley Kaufman  
Stacie Ray  
Colleen Richart  
Pete Seiler

**Guests**

Kelly Malcom, UNL Student, HearU  
Amber McLaughlin, Parent

**Liaisons**

Julie Docter

**Liaisons – via Zoom Teleconference**

Sara Peterson

**Interpreters**

Ben Sparks  
Jamy Elker

**Staff**

Brenda Coufal  
Jim Beavers  
MeLissa Butler  
Shelli Janning  
Nicole Swanson

**Newborn Screening Staff**

Krystal Baumert  
Julie Luedtke

**Meeting start time** – The meeting was called to order by Committee Chair, Dr. Stacie Ray at 12:02 pm.

**Open Meeting Act** – Presented at the beginning of Advisory Committee Meeting by Dr. Stacie Ray.

**1. Welcome and Introductions**

Dr. Stacie Ray Chair for the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program Advisory Committee, welcomed all Committee members, staff, and guests.

**2. Review of Agenda, changes**

There were no changes to the agenda.

**3. Review of November 16, 2017 Minutes – Action**

The Meeting Minutes from the November 16, 2017 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 Nina Baker, seconded by Kim-Jae Kang, and unanimously approved by the committee members.

**4. 2018 EHDI Annual Meeting Overview & Lessons Learned (Parent Perspective)**

Amber McLaughlin, NE-EHDI Family Engagement and Leadership Development Scholarship recipient presented information on her experience at the EHDI Annual Meeting held March 18-20, 2018 in Denver, Colorado. Amber shared photos she took at the conference, and the highlights of the sessions she attended.

Amber chose to attend Technology 101 because her daughter is due for a new hearing aid soon. She appreciated the information presented because one of the handouts outlined a list of pros and cons for

each brand of hearing aid, along with a list of troubleshooting basics. One interesting pointer she gleaned from the presentation was that when you take the sticker off of a hearing aid battery, you should leave it open to the air for three to four minutes to allow it to activate. This will increase the life of the battery.

Amber also commented that she enjoyed looking at the various poster presentations. One that was very helpful for her was titled *Creating Language Activities for Engaging Parents of Children Who are Deaf or Hard of Hearing in Daily Language Development*. Amber felt that this particular poster was especially helpful because it talked about the importance of language and communication between parents and their hard of hearing children.

The session called *No Holding Back: Providing Resources for the Whole Family* focused on family education topics like language ideas for building your toddlers vocabulary, visual learning, ASL development, and Social-Emotional health.

Amber added that she really enjoyed going through the exhibitor hall, and that it took her all three days of the conference to see everything. Her daughters loved going through the exhibits with her because of all the paper, pens, and other trinkets that the exhibitors gave out. One exhibit Amber particularly enjoyed was the CDC booth with information about how the CDC support programs to help babies thrive.

Another session that Amber really appreciated was *IDEA and Advocacy, Protecting the Parent/School Relationship*. Amber's daughter had an IEP meeting about three weeks after the conference, so she felt fortunate to be able to attend this session to get ideas and information to help her prepare, as she is currently trying to get CART and a sign language interpreter in the classroom for her daughter.

Amber also enjoyed the session titled *Tips for Creating a Deaf/Hard of Hearing Friendly Home Environment*, adding that the practical advice given by the presenter, Robin Getz, has helped her to see how she can make both home and school an environment that her daughter can thrive in. Amber added that she really appreciated having CART available for each session, and that even she as a hearing person benefited from this service because if there was a word that she missed, she could just look up at the captioning to catch it. She used this as an example when advocating for services in her daughter's IEP meeting. Amber added that early in their journey, she and her husband attended Roots and Wings Parent Weekend, and this is where she first heard another parent say that you should never say "never mind" if your hard of hearing child misses something in a conversation, and that is still a rule in their house to this day. The presenter also reiterated the importance of never dismissing your child's opportunity to hear every part of the conversation. Amber shared that incidental learning opportunities are the primary reason why she asked for a sign language interpreter in the classroom for her daughter. Her daughter already uses an FM system, but even with that, she misses out on incidental learning opportunities from peers and adults that are not using the FM at that moment.

Amber added that she brought her daughter to the presentation called *Who Am I? A Deaf identity Crisis*, and she was so glad that she did because the speaker was a woman who is hard of hearing and wears hearing aids. She talked about how she didn't fit in with the hearing world as a child, and struggles to fit in with the Deaf community as an adult. Amber added that she is afraid her daughter will also have this type of identity crisis since she primarily uses her hearing aids. Amber was happy that her daughter got the opportunity to see so many people like her at this meeting, and to be exposed to the deaf and hard of hearing world so that she knows that she has a place where she fits and belongs. Amber wants her daughter to know that the world is her oyster, and there's nothing she cannot do.

Amber highlighted some of the brochures and resources she collected from the exhibits. She thanked the committee for the opportunity to attend the conference and bring her family along.

Shelli Janning thanked Amber for sharing information and pictures from the conference on the Nebraska Hands and Voices Facebook page so other parents could see the information she gathered at the conference.

## **5. “Thank You” recognition & Advisory Member status**

Brenda Coufal, Program Manager for the NE-EHDI program thanked Linsay Darnall Jr. for serving as Chair, and Kim-Jae Kang for serving as Vice Chair for the 2015-2017 term, and thanked them for the warm welcome they extended to her when she started as the program manager. Brenda presented both Linsay and Kim-Jae with a certificate and gift card.

Brenda welcomed Stacie Ray as the new Chair, and Katie Brennan as the Vice Chair.

She also updated the committee on changes to the membership roster. Changes included:

- Brenda Hoover who served for two years is stepping down, being replaced by Ashley Kaufman.
- Rhonda Fleisher is retiring, and will be replaced by Sue Czaplewski who will join the committee in the fall.
- Dr Rick Kang is transitioning into retirement over the next year, and has stepped down from serving on the committee. Since Dr. Kang was serving as the Nebraska Chapter Champion, the American Academy of Pediatrics is currently searching for his replacement, and once this is announced Brenda will inform the committee. On behalf of the committee, Brenda expressed her appreciation to Dr. Kang for all the work he has done as Chapter Champion.
- Dr Steve Boney is also retiring, and will no longer be serving on the committee.
- Two new members will be joining the committee in the fall.
  - Johnna Lygrisse, the mother of a child who is hard of hearing.
  - Jayden Jensen, a college student who will be sharing her perspective and experiences as a young adult who is deaf.

Brenda also stated to keep the meeting on track, speakers have been allotted a certain amount of time on the agenda. Nicole Swanson will be holding up time cards to let the speakers know how much time they have left.

Any agenda items that are discussed too long will be decided by the committee to table until the next meeting, or schedule a sub meeting, or the discussion can continue via email.

## **6. EHDI at a Global Level**

Dr. Stacie Ray presented information about EHDI at a Global Level, HearU’s international efforts to serve individuals who are deaf or hard of hearing in Nicaragua.

Stacie’s stated that her professional focus has been helping children who cannot afford hearing aids to obtain the technology they need. Once she successfully got HearU going in Nebraska, she then decided to focus on what EHDI looks like globally. Stacie found data from the World Health Organization (WHO) that shows over 466 million people worldwide are deaf or hard of hearing, with 7% of those individuals being children. This statistic showed that the ages of those children range between 5-14 years, but there is no data in most countries on children under the age of five because EHDI is not worldwide.

In 1995 WHO recommended that a policy of universal neonatal screening (UNS) be adopted in all countries. It is estimated that the number of individuals with disabling hearing loss increased from 42 million

in 1985 to 360 million in 2011, and in 2018 that numbers has now increased to 466. The number is increasing not because more people are becoming deaf or hard of hearing, but because there are more screening programs available.

In 2015, the WHO surveyed all countries regarding the status of their newborn hearing screening programs. One hundred forty three (143) countries responded. More than half of the countries who responded had some form of a UNS program, either regionally or national. The data showed that the effectiveness of a screening program is higher if there is a national program, and if the screening was mandated. Additional findings showed that there is a lack of UNS in low income countries.

There has been a great deal of success with UNS in the United States. In 1989, less than 3% of newborns were being screening. Now nationwide, over 98% are routinely being screened. One major contributing factor is the number of stakeholders who are actively involved in all aspects of the UNS process. In the United States there are rooms full of stakeholders, just like those on our committee. Another factor is having buy in from various groups including parents, professionals in the educational system, and policy initiatives by governments, professional associations, legislation, and advocacy groups. Technology has also improved. Demonstrated success to early implementations has also been a contributing factor.

Nicaragua is the second poorest country in the western hemisphere, and accessibility to healthcare is poor. There is one known audiologist in the entire country. Stacie began to examine why we're so successful in the United States, and why Nicaragua has so many challenges. She found many factors, including low financial resources, limited training programs, difficulty linking to existing health care because of poorly developed health care systems, difficulties with affordable transportation, lack of motivation due to their culture and/or being unsure if interventions will help. There is also an absence of political will; even if the government wants to buy in, financially they will not delegate the resources.

Stacie examined two case studies: the first was a child born in Nebraska who was screened by one month, diagnosed by three months, and had access to ASL and amplification by age six months. That child has access to language right away, and full language by age five. The second case study was a child born in Nicaragua. The child was identified at the age of five and fitted with hearing aids. The child has very little spoken or sign language.

Stacie discussed ways EHQI can be increased globally, and how humanitarian efforts can help build capacity in low income countries. In order to continue to build capacity for sustainability in Nicaragua, Stacie stated that she will consider herself a success when she works her way out of a job in humanitarian audiology.

Julie Luedtke asked if Stacie is aware of other organizations who are doing similar humanitarian audiology efforts. Stacie said that there are many all over the world, however their programs focus only on serving underserved populations, not sustainability. HearU International is doing more, because they are working towards building capacity and training others, so that when Stacie is gone, there is still audiology in Nicaragua. Julie added that HearU International seems very similar to *Doctors Without Borders*. There are parallels in the metabolic screening world, where organizations have gone in and helped to build and develop programs. Some of these programs are funded by the Department of Energy, so Stacie could possibly look into funding through that agency. Stacie thanked Julie for the suggestion, adding that they're always looking for funding because global grants are competitive and continue to be a challenge.

Linsay Darnall Jr. stated that he has a friend who has served on two different organizations who have traveled to other countries to educate children who are deaf or hard of hearing, and exposed them to sign languages. His friends have told him that there are frustrations, including that when they arrive and they identify who they want to work with, it's usually children with hearing aids. Organizations seem to come to

these villages, give the kids hearing aids, and then leave. But, there is no education or exposure to sign language. Often the hearing aids don't have batteries. Linsay suggested that programs like HearU International could include Deaf adults who could help teach the kids sign language. Stacie stated that when she started HearU International before she even went, she researched existing resources in the country like schools for the deaf to see if there are areas where people could have access to sign language, and whether there even was a national sign language in Nicaragua. Stacie knew ahead of time that not every child would benefit from hearing aids. Stacie added that she continues to build collaborative relationships with the community.

Pete Seiler suggested that Stacie could collaborate with Dr. Julie Delkamiller who also does some outreach work in Nicaragua, she may have resources that could help Stacie.

Pete added that Nicaragua does have a national sign language and a school for the deaf, but he's not sure if there are any early childhood language development experts there. Perhaps HearU International could look into adding some language experts to their professional group. Pete added that if a person is deaf, there are many people in the US who can help out deaf individuals in other countries.

Stacie responded that she has had many conversations with many people throughout the university system to see how they can cross collaborate, and she does work with Julie Delkamiller and Anne Coine.

Pete reinforced what Linsay had stated earlier, adding that there should be professionals trained in language that should be involved in these types of outreach efforts, because training is critical.

## **7. Program Update and Action Items**

Brenda Coufal, Program Manager for the NE-EHDI program updated the committee on current program activities. Brenda also addressed action items needing attention from the committee.

Brenda reviewed the current funding sources for the EHDI Program, adding that she got a few ideas from other program coordinators at the Annual EHDI meeting in Denver, so she will be checking into those opportunities. She then asked the committee if they have any ideas about sustainability. MeLissa Butler discussed the idea about receiving a fee from the hospitals for the newborn hearing screening to help fund the program. Laura Beshaler asked who pays the fee. MeLissa stated that she thinks the insurance companies do. Brenda added that the details regarding who pays the fee needs to be worked out in the legislation, if changes to legislation are pursued.

Brenda briefly reviewed the current HRSA and CDC grant goals.

Brenda shared highlights from the Audiology Clinic Survey that was sent out by NE-EHDI in April, as detailed in the handout. Julie commented on question #5, which asked the audiologists to rate their confidence in their ability to implement next steps for the child after a confirmatory diagnostic evaluation. Under the section that asked them to rate their confidence in acting as the professional case manager, she pointed out that the way the question was asked may have prompted the audiologist to answer from the perspective of them feeling that it is not their role. Brenda responded that is the reason we want to follow up face to face with audiologists individually, so we can gather more information.

Pete Seiler asked about the 4<sup>th</sup> bullet on question 5, regarding discussing communication options and educating parents, adding that he thinks these should be separated. There is no way to know what the competence is addressing. Is it asking if they are confident addressing communication options, or if they are confident explaining things like cochlear implants or hearing aids? Brenda agreed that on future surveys, these competencies will be separated out.

Pete added that SLP's and audiologists are not experts in sign language, so there needs to be a competent professional that is an expert in things like signing and speech who discussed communication options with families. Brenda responded that these professionals can still be the ones who connect families with appropriate resources.

Kristin Jolkowski asked about question 3 that asks about different services available at the audiology clinic, she wondered if EHDI was able to get geographic information on the areas where specific services are available. Of the audiologists who responded, 53% indicated that their facility offers sedated ABR's, but those services are only available in Omaha, so the data looks skewed. Brenda stated that is a good point, and there is demographic information available in the survey data so we can analyze it further and line up what services are available. That information can be shared upon request.

Pete asked what EHDI will do with the information from this survey. Brenda stated that EHDI will visit each of the main six clinics who see pediatric patients in Nebraska to help audiologists work through issues, to strengthen their program, and make sure all facilities know about the JCIH 1-3-6, and protocols. Pete asked what type of trainings will be done. Brenda stated that EHDI will develop the trainings once we get more information from the face to face meetings.

Kim-Jae added that it would be helpful for EHDI to start these audiology trainings at the university level so we can train students early in their career. At annual statewide audiology conferences, there should be mandatory review training annually to keep audiologists up to date. And, audiologists who come in from other states to practice in Nebraska should have a mandatory training so they know how to do things here. Brenda commented that MeLissa Butler presented at NSLHA in 2017, and also exhibited. EHDI will exhibit at NSLHA in 2018.

Additional updates to audiologists that have occurred since the last EHDI meeting were an email blast to audiologists in May and an article in the NSLHA newsletter for Better Speech and Hearing Month. Both of these were in collaboration with EDN, which included EHDI educational information, importance of early intervention, and process for EDN referrals to Audiologists.

In May and June, EHDI plans to meet with audiologists to follow up on their survey responses. EHDI will also meet with Mary Pat Moeller on 05/11/2018 to discuss Audiology and ENT survey data she has gathered.

In past meetings, the difficulty with getting information to ENT's has been discussed. Dr. Stacie Ray has contacts with two ENTs, and EHDI will attempt to reach out to them as a starting point to figure out how we can better communicate and collaborate with this group.

EHDI met with EDN in February and April of 2018 to discuss referral process, EDN data, and reports. These meetings resulted in a revised referral process for early intervention to EDN; EDN will provide a quarterly report of the children identified as D/HH who are less than age 3 in the EDN CONNECT system for NE-EHDI to check for missing Dx/EI infants who should be in the NE-EHDI data system; and the information EDN shares on their website for referrals for EDN diagnosed as D/HH & the info shared between EHDI & EDN has been streamlined.

Kristin Jolkowski asked if every child that is deaf or hard of hearing ends up in the EDN data system as deaf or hard of hearing, or are they just categorized as developmental delay? Julie Docter responded that it's possible that they may be categorized as development delayed only, but there is a special field within the EDN database where the services coordinators are supposed to indicate hearing loss. Pete asked that members of the committee refrain from using the term "hearing loss". The child has not lost their hearing,

and he believes that use of the term is inappropriate. He asked that the committee try to use more positive language, and use the terms deaf or hard of hearing.

NSLHA has invited EHDI to share information on their website. Brenda asked the committee if they have ideas that would benefit audiologists and SLPs. Ashley Kaufmann suggested adding EDN information to the NSLHA website so audiologists and SLPs know where to refer to, and how to make a referral.

Brenda discussed future activities include:

- NE-EHDI Exhibits – September 27 & 28, 2018
  - NSLHA Conference
  - Nebraska Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) Conference
- Presentation at the October 2018 Nebraska Nurses Association Conference

Brenda also discussed new collaborations:

- Maternal Infant Childhood Home Visiting (N-MIECHV) Program
- Women, Infants and Children (WIC) Supplemental Nutrition Program,
  - Both N-MIECHV and WIC will provide the NE-EHDI “Can Your Baby Hear” brochure to pregnant clients. Once procedures are approved to ensure HIPAA compliance, they will also check their database for contact information for families we can’t locate, and stress the importance of screening, follow-up, diagnostic evaluation, and EI as needed.
- EHDI is meeting with Family Care Enhancement Project (FCEP) at the Munroe-Meyer Institute with UNMC May 11 to discuss collaboration efforts.

Brenda shared that other suggestions made at the November 2017 meeting are still being pursued. These include:

- Lincoln Public Schools Special Education Program Meeting
- Complete Children’s Health monthly QI meeting presentations
- Children’s Hospital trainings for pediatricians statewide and Children’s Physicians newsletter
  - Laura added that this is part of a larger project to have better communication, and develop a standard protocol across all Children’s clinics. It’s a big project, so it will be in the works for a long time. The newsletter would be a great place to start sharing information.
- Contacting facilities with birthing classes and nurse midwives
- Early Childhood Institute:
  - Brenda asked if anyone has a contact at the early childhood institute. Julie Doctor commented that the *Nebraska Young Child Institute Conference* will be held in June in Kearney, and EHDI could have an exhibit. EDN has partnered with several other agencies to sponsor an exhibit at this conference the past several years. If EHDI is interested, Julie can help with contacts.

Brenda asked the committee if they have ideas about other pertinent organizations NE-EHDI could contact for sharing information.

- Ashley Kaufmann suggested exhibiting at newborn expos around the state. This may be an opportunity to educate parents about the newborn hearing screening before they go to the hospital so they can advocate for themselves in the hospital. Kim-Jae added that Boys Town, Children's and Methodist Women's Hospital hold newborn expos.

Brenda discussed the Year Two Family Support activities, as required by the HRSA Grant. NE-EHDI will continue to collaborate with Hands & Voices and HearU Nebraska, and search for opportunities to collaborate with other partners as well. Not all collaborations for year two of the HRSA grant have been determined. Some ideas for future events are as follows:

- Future family support activities will have information on ASL and Deaf culture incorporated into the curriculum.
- Brenda will contact Cathy Carotta at Boys Town to see if Roots and Wings 2019 is being planned.
- A dad event may be possibility since sometimes dads don't feel like they are as involved as they could be.

Brenda asked the committee if they have ideas about how NE-EHDI could partner more with the Nebraska Commission for the Deaf and Hard of hearing to involve the Deaf and Hard of Hearing Community more. Even though the EHDI budget is limited, she would still like to find ways that EHDI could support events like volunteering. Due to time constraints, EHDI will have a side meeting with members who represent the Deaf Community. Lindsay stated that he has a list of ideas that he would like to share with EHDI after the meeting.

Brenda also mentioned that due to budget cuts, advisory meetings have been reduced from four per year to two per year, however, EHDI still wants to ensure that we are utilizing the skills and expertise that each of our members bring to the committee. Brenda asked for ideas on ways that members feel they could be more actively involved.

Pete Seiler suggested that the committee discuss a bilingual approach for kids who are deaf or hard of hearing entering kindergarten. Many teachers aren't educated about how to teach deaf children, so the deaf community has some insights that they could share.

Brenda added that she wants to work with all members as much as possible, but cannot guarantee that we can do everything that is suggested, however, EHDI is an unbiased program and we need to make sure that all information and resources are shared in an unbiased way.

Due to time constraints, Brenda was unable to finish her presentation, but stated that if there is time at the end of the meeting, she will finish.

Brenda concluded by announcing to the committee that she welcomed her first grandbaby in April. The committee congratulated Brenda on her grandson.

Nina Baker asked if her grandson passed the hearing screening. Brenda stated that he did pass, and she was actually in the room when they brought him back after the hearing screening was done, so she was able to ask the hospital staff questions.

## **8. Follow-Up for EHDI Report & Family Support Events Update**

Shelli Janning, Guide By Your Side (GBYS) Program Coordinator and NE-EHDI Program Community Outreach Coordinator updated the committee on her work with EHDI, and the family support events GBYS helps coordinate for families in Nebraska.

Shelli shared that she recently connected with a mom through GBYS whose child had referred on the newborn hearing screening. Because she connected with this mom early in the process through her work with EHDI, she was able to accompany her to the child's confirmatory diagnostic ABR at Boys Town. In her conversations with mom prior to the appointment, Shelli could tell that this mother was in denial. The family has a history of small ear canals on the baby's father's side of the family, and the mom thought that maybe that was the problem. She had hoped the baby would show normal hearing at the confirmatory evaluation. The results of the ABR showed that the baby was profoundly deaf, and the mother was shocked. The audiologist did a wonderful job of explaining every option, from ASL to hearing aids and cochlear implants. However, due to her emotional state, the mom was having a very difficult time processing what the audiologist was explaining to her. Shelli was glad that she was able to be there for the mom, and take notes during the appointment. After the meeting, Shelli sent her notes to the mother, and was happy to find out that the mom was sharing the information with many of her family and friends. Shelli added that because of the collaboration between GBYS and EHDI, this mom had an amazing experience, and was able to have parent to parent support at the confirmatory evaluation. The collaborations are truly benefiting families in Nebraska.

Shelli went on to discuss the information provided in the handouts regarding the number of families served, the number of Parent Guides in Nebraska, and the family support events that have taken place.

## **9. HearU/Hearing Aid Bank Update**

Kelly Malcom, UNL Graduate Student and HearU Graduate Assistant, presented the HearU statistics for January 1, 2018 to April 23, 2018, as detailed in the handout.

Kelly discussed the new financial criteria as of 01/01/2018. So far, there have been five denials. Two denials were over the income level, and three possibly qualified for Medicaid. If they don't qualify for Medicaid they can come back. Those families do have the option of receiving trial HA's in the interim period of waiting for Medicaid approval.

Stacie Ray added that HearU met with Julie Docter from EDN to discuss the need for more resource coordinators to help families, since the audiologist can't always coordinate resources for assistance with purchasing devices. In the future, HearU will be working more closely with EDN to facilitate this process.

Also, a donor contacted HearU and is providing \$15,000 as a matching gift for HearU's 10<sup>th</sup> anniversary, so they will hold a benefit in connection with the pledge to try and keep HearU going.

## **10. Deaf Community Activities Update**

Pete Seiler gave the committee an overview of the Nebraska Association of the Deaf (NAD), as detailed in the PowerPoint presentation.

Pete stated that the Vision Statement of the NAD focuses on ensuring that both Deaf and hearing people are on equal terms. Pete shared that at his recent doctor's appointment, there was no interpreter at the doctor's office, and he did not request one. He told his doctor that they could just communicate by writing on a notepad. Pete noticed that his doctor was skipping questions on a questionnaire, so Pete told his doctor that he wanted his co-pay back if he could not start writing the whole conversation. Pete added that this shows that many deaf people don't advocate for themselves because they are used to being oppressed.

Pete stated that the NAD wants equal information to be available to deaf individuals. He pointed out that things like weather alerts and movies cater to the hearing population. When the deaf community asks for accommodations, like captioning at movies, the response is that the hearing community prefers no

captions. Pete believes that making captions a standard would improve people's English skills, along with giving the deaf community access.

Pete discussed previous and ongoing activities provided by the NAD including Deaf Day at the Zoo and Autumn Blaze. One key activity that the NAD focuses on is education advocacy. The NAD was able to successfully advocate to raise the EIPA rated skill level for educational interpreters to 4.0. Pete added that the deaf educational advocate's job is not to show families options, but to show them what can be done with language, and that language is a right.

Pete discussed future efforts that will be pursued by the NAD including working with the state and local prisons to ensure that basic rights are granted to deaf and hard of hearing prisoners, developing a bill to promote and support language acquisition efforts for deaf and hard of hearing children ages 0-5 years, requiring all public sports venues to provide open captions on TV's and screens, and requiring movie theaters to offer on a regular basis, a reasonable time and day for open captions of current movies.

Stacie Ray asked Pete how many NAD members there are in Nebraska. Pete replied there are about 150 members. Linsay added that there are 150 paid members, but they represent 158,000 Nebraskans who are deaf or hard of hearing.

#### **11. NE-EHDI Learning Communities Update & Poster Presentation**

MeLissa Butler, NE-EHDI Community Health Educator Sr. updated the committee on the two learning communities currently being coordinated by the NE-EHDI Program.

MeLissa reviewed the Hospital Training Learning Community's purpose, which is to develop a script and training protocol that helps hospital staff understand the best way to communicate results of the newborn hearing screening to families, especially when a baby refers inpatient. MeLissa reviewed the roster, highlighting that the parents who had a negative experience inpatient are key stakeholders in this initiative.

MeLissa shared that, as part of Aaron Beard's required project for the parent stipend he received to attend the 2017 EHDI Annual Meeting, he and his wife Angie developed the script for the video with input of all the work group members.

Linsay Darnall Jr. asked if either he or Pete could review the script to ensure that the Deaf perspective is respected. MeLissa responded that, Colleen Richart did review the script and both she and her husband Steve offered quite a bit of valuable insight regarding the Deaf perspective, and changes were made to the script to ensure that the information is sensitive all around.

MeLissa also announced that Boys Town has agreed to produce a training video for this project. Aaron and Angie will "narrate" the video, and stock photography will be used to fill in additional casting needs. The video should be done before the end of the year, hopefully sooner.

MeLissa went on to discuss the Western Nebraska Learning Community. Maureen Ideker from Great Plains Tele-health Resource and Assistance Center (gpTRAC) works on a federal grant that serves as a resource for tele-health. She helped MN-EHDI set up their tele-audiology program, and she has obligated 40 hours to our project so we are very grateful to have her assistance in this process.

ESU #13 has volunteered to be the remote location. They have offices in Scottsbluff, Sidney & Chadron, so there is opportunity to serve a larger geographical area of western Nebraska. Originally, Boys Town had volunteered to be the originating sight, but after reviewing the project with their board, they decided that they cannot participate or be the originating site. Maureen will be talking with UNL & Children's to see if either place is interested in being the originating site. MeLissa acknowledged that there is a great need for services out west, so she is hopeful that this tele-health project can be successfully implemented soon.

MeLissa also discussed highlights from her poster about Lost to Follow Up that she presented at the EHDI annual meeting in Denver. The poster focused on Lost to Follow-up, and detailed the steps NE-EHDI has taken to reduce the number of children who are Lost to Follow-up in Nebraska.

## **12. NE-EHDI Statistics and Lost to Follow-up Information**

Jim Beavers presented information on the NE-EHDI 2016 DOB Statistics, as detailed in the handouts.

Stacie Ray asked about slide #2 which shows the percentage of children who are greater than 90 days of age at confirmatory diagnosis, requesting that Jim tease out geographic information or facility information so we can identify where the lag time is. Jim responded that about 85% of children in Nebraska are identified at Boys Town. Laura Beshaler asked if this statistic takes into consideration kids with chronic conductive hearing loss. Jim stated that those children are included in these stats, but the statewide averages are compared to nationwide averages and every state faces the same issue. MeLissa Butler added that breaking the data out by facility may unfairly penalize Boys Town, because often children in smaller towns will start at the local ENT office before they go to Boys Town, so they are often greater than 90 days of age before they even get to Boys Town. Jim stated that he will think about how to do some additional analysis before the next meeting to try and identify gaps and barriers to confirmatory diagnosis by 90 days of age.

Nina Baker pointed out that if 85%-90% are going to Boys Town, and if we break down the rest of the data by facility in the smaller towns where the child is tested, it could become a breach of confidentiality.

## **13. Other**

Brenda continued her presentation from earlier in the meeting, asking the committee for input on future presentations.

- Linsay suggested asking a few Junior NAD members to share their perspectives.
- Pete mentioned that earlier in the meeting, one of the learning communities talked about parents who had a negative experience in the hospital with the newborn hearing screening, and suggested that maybe they could share their experience with the committee. MeLissa stated that two of the three parents on the learning community already presented their stories at the November, 2017 meeting, and two parents are currently members of the committee.

Brenda asked if the committee has a preference regarding who presents at the November meeting. Stacie asked EDN to present. Julie Docter agreed that EDN could present at the next meeting.

Brenda asked the committee if they felt the Nebraska Children's Home Society meeting room met the needs of all members. All members agreed that they like the meeting space, and would like to have future meetings held there.

Brenda Coufal asked if there were any other agenda items the committee would like to discuss.

Linsay Darnall Jr. shared that he believes that EHDI is a great way to identify infants who are deaf or hard of hearing and get them to appropriate services like language acquisition and education so they can have a better life. Historically, when EHDI started, we had a goal. Over the years, socializing with the Deaf community on a national level and the state level, EHDI's goal is broadening. The main goal is screening and identifying deaf or hard of hearing infants. However, Linsay is still noticing that people, including himself still carry bias related to how they were raised. Hearing are raised from the experience of being able to hear, and the Deaf community has a deaf experience. We come together, socialize, and learn from one another for the benefit of deaf and hard of hearing children. However, these biases will pop up during

meetings, and this is something that everyone needs to be careful of. For the Deaf population, those biases are not going to help, they're going to hurt. So, that is why from time to time the Deaf members of the committee will speak up to make sure that everything is kosher so that deaf and hard of hearing children have a great upbringing and a great experience growing up through the support of everyone the committee represents. Earlier in the meeting when Brenda announced the birth of her grandchild, he knows that the committee members meant well when they joked around and asked if her grandson passed his hearing screening, and there was a celebratory response when they heard that he did. Internally, Linsay's heart sank when the members celebrated that, because it made him wonder what is wrong with being Deaf. Linsay feels that he and Pete are living proof that it's okay to be Deaf. Linsay asked the committee to be considerate of the Deaf members, and to understand that being Deaf is also something to be celebrated. Deaf people in the state of Nebraska have the right to receive equal access to opportunities. Linsay added that he would like to see the committee put forth efforts to reduce the use of the phrase "hearing loss". Linsay understands that biases will appear, but they need to be kept in check. We are all equal, so we all need to work together to make sure everyone has a positive experience.

Shelli Janning admitted that she uses the phrase "hearing loss" a lot. Her daughter identifies herself as having hearing loss. When Shelli and her daughter use that phrase, they do not view it as something negative. The other day, Shelli asked her daughter what she was most proud of in life, and Brooke's response was that she was most proud of her hearing loss. Shelli added that she was surprised, because Brooke has so many talents, she's an amazing pitcher and she's very smart. Shelli recognizes that the phrase is not "PC" in the Deaf world, but in her family it is not a negative term. Shelli concluded by saying that she also understands that it is important to be sensitive to others feelings on the subject.

Stacie Ray clarified that the committee was celebrating the birth of Brenda's grandchild with her and that she was able to be there when they brought the results back since she is the EHDI Coordinator, not the fact that he passed his hearing screening. Not one person on the committee celebrated that fact that the baby passed his hearing screening. So, if Linsay took offense to what was said or done, she hoped that she could clear up what the intent was and what actually took place.

Linsay responded that he understands we all mean well, it was just a momentary "whoa" where some members of the committee almost breached the line and celebrated that the baby passed the hearing screening. Linsay added that he is very happy for Brenda.

Brenda added that she would love her grandbaby whether he was hearing or deaf. Linsay emphasized that he didn't say that the group got to the point of celebrating, but he felt that it could have gotten to that point.

Nina Baker thanked Linsay for bringing this topic up, but she also wanted to explain her position as a parent advocate for over 35 years. One of the first things she likes to know is that if a child has an issue, both the family and child will receive the services they need, that everyone on the committee works to provide. So, her questions are asked with the intent of focus on whether or not the child will have the opportunity to get the services they need.

Pete Seiler shared that when he was younger, his parents emphasized that he was deaf. Well-meaning people would refer to him as hard of hearing, with the idea that they were being nice because the more hearing you have, the better person you are. Pete then compared that to a white person looking down on a non-white person, or a more masculine person feeling that are better than a more feminine person. There has always been a focus on what the dominant group was. When people would ask him if he was hard of hearing, he would respond that he was deaf. When he would question his parents about these exchanges, and ask why people would say he was hard of hearing, his mother told him that they were wrong, they were trying to make him feel bad. He is deaf and that was okay. It made him feel good about who he was. When

people would come up to Pete and say they were sorry that he couldn't hear, he would respond by saying that they should be upset with God, because in the bible at Exodus 4:11, it says that God made them deaf, so if they have a problem with it they need to bring it up to God, because God made him that way. So if they feel sorry for him, they could bring it up to God. The point that the Deaf community is trying to make when they emphasize that they don't want the phrase "hearing loss" used is that it implies they have lost something, and they are not normal anymore. Pete then compared it to someone being born female having "male loss", adding that it doesn't sound right and its negative, like the male is more important. So, he is trying to help children grow and feel good about themselves, and they're emphasizing a need for change. Pete grew up in a hearing family, Lindsay grew up in a Deaf family, but they both feel the same way about that term.

Brenda thanked everyone for their feedback, and concluded the discussion by stating that she feels everyone in the room wants what is best for all children who are deaf or hard of hearing, and this committee works hard to collaborate towards achieving that goal. Families have the right to choose for their child, and when their child is able to make choices for themselves, they have the right to choose how they identify and what works best for them.

#### **14. Adjourn**

A motion to adjourn the meeting was made by Laura Beshaler and seconded by Kristin Jolkowski. The meeting was adjourned at 4:02 pm.

#### **Next Meeting:**

- November 8, 2018 - NET Nebraska, Lincoln NE
- May 9, 2019 - Nebraska Children's Home Society, Omaha NE
- November 14, 2019 - NET Nebraska, Lincoln NE

Respectfully submitted by MeLissa Butler, Community Health Educator Senior