

The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

November 8, 2018

Meeting Minutes

12:00 pm – 3:53 pm

Nebraska Educational Television

Attending:

Members

Nina Baker
Laura Beshaler
Katie Brennan
Jenna Browning
Lindsay Darnall Jr.
Nancy Hengelfelt
Jayden Jensen
Kristin Jolkowski
Ashley Kaufmann
Kelly Rausch
Stacie Ray
Colleen Richart
Pam Zegers

Guests

Kelly Malcom, UNL Student, HearU
Manuel Vicente, Boys Town

Liaisons

Julie Docter
Cole Johnson

Interpreters

Ben Sparks
Pam Duncan

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 12:00 pm.

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

1. Welcome and Introductions

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

Brenda Coufal, NE-EHDI program manager stated that after the May 2018 EHDI Advisory Meeting, she evaluated the meeting and the feedback received from members to reflect on how we can improve the advisory meeting environment so it is a place of respect for ALL members.

She feels it is her responsibility as the EHDI Coordinator to ensure the advisory meetings are a “safe” environment for ALL members to share ideas, experiences, and ask questions, because this is the only way the NE-EHDI program can continue to improve.

Her goal is to have a meeting environment that focuses on the NE-EHDI mission, where all members have the opportunity to learn about the parent perspective, to learn about deaf culture and the deaf and hard of hearing perspective, and learn about the current work of medical professionals and early intervention professionals. Above all the meeting environment should be a place where members are not worried about saying something wrong. Brenda wants members to feel comfortable asking questions and providing information during the meeting so we can continually improve our follow-up processes to educate families about the importance of the newborn hearing screening and the next steps. Brenda strives for the meetings to be an opportunity to inform families about available services and connect children who are D/HH with appropriate services so their child can be happy, healthy, confident, and successful.

NE-EHDI had previously developed the following statement that was read at the May 2018 Advisory Meeting:

“The NE-EHDI Advisory Committee works to improve the lives of all Nebraska children who are Deaf or Hard of Hearing by recommending policy that promotes diversity, equality, awareness, and access. NE-EHDI is an unbiased program that informs families of available resources and we respect their right to determine what is best for their family. Thank you members for providing your valuable perspective.”

After the May, 2018 meeting, Brenda received feedback from many members, and wanted to discuss with the group why she feels additional information should be added to the statement.

The EHDI advisory members serve in a variety of different roles assisting children who are Deaf and Hard of Hearing. All members' roles are very important. There are terms such as “hearing loss” that are viewed differently by individuals, depending on their role and background.

- Medical professionals use hearing loss as a diagnostic term.
- A parent may use hearing loss when discussing their child's hearing as they are trying to learn as much as they can about helping their child on this journey, which may be new to all of them.
- Hearing loss is also used when referring to late onset or progressive hearing loss.
- Members from the Deaf Community perceive the term “hearing loss” as audist due to people using such terms in a condescending way, or to feel sorry for them.

The following is the new statement EHDI would like the Chair to read before each NE-EHDI Advisory Meeting:

“The NE-EHDI Advisory Committee works to improve the lives of all Nebraska children who are Deaf or Hard of Hearing by recommending policy that promotes diversity, equality, awareness, and access. NE-EHDI is an unbiased program that informs families of available resources and we respect their right to determine what is best for their family.

Due to budget, there are only two advisory committee meetings per year. To help the committee stay focused on improving the work of the NE-EHDI program, members will strive not to use the terms “hearing loss” or “hearing impaired”. This may be difficult since some members may not view these as negative terms, however we recognize that those terms are negative for other members. If hearing loss or hearing impaired are inadvertently used during the EHDI Advisory meeting, all members and attendees will recognize that it is not the intent to be negative or disrespectful.”

2. Review of Agenda, changes

There were no changes to the agenda.

3. Review of May 3, 2018 Minutes – Action

The Meeting Minutes from the May 3, 2018 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 Katie Brennan, and unanimously approved by the committee members.

4. NE-EHDI Program Update and Action Items

Brenda Coufal, Program Manager for the NE-EHDI program reviewed changes to the membership roster:

- Welcome to new member Jayden Jensen, who is a college student at UNL and represents the deaf/hard of hearing community.
- Johnna Lygrisse, parent of a child who is hard of hearing will be joining the committee in May, 2019.
- Jenny Corum moved out of state, and will be replaced by a designated representative from the NCDHH when one is identified.
- Dr. Rick Kang, NE-EHDI Chapter Champion has stepped down. Brenda is working with AAP to identify a new Chapter Champion, and it will be announced when finalized.

There have been no changes with the open meetings act. Members still need to attend 50% of the meetings in person to be voting members. There are challenges with members attending meetings via teleconference. These restrictions make it difficult for people in central and western Nebraska to participate in the committee. Brenda

asked for feedback regarding whether there is better technology than Zoom for meetings. Nobody in attendance had any better suggestions at the time, so Brenda asked that if someone thinks of anything, please let her know. Brenda emphasized how important it is that Sara Peterson continues as a liaison, because she represents western Nebraska, and keeps the committee informed of the needs and challenges in that part of the state.

Brenda refreshed the committee on EHDl funding sources. Currently, HRSA provides \$250,000/year, CDC provides \$150,000/year and MCH Title V Block Grant provides funding as needed, depending on available funds. From July 2017-June 2018, EHDl utilized \$20,659 in Title V dollars. Due to recent funding restrictions, EHDl has determined that it is necessary to address sustainability. Some states receive a fee from newborn screening for hearing screening to help fund their program. Colorado EHDl passed legislation in July 2018 to receive a \$4/baby fee for the hearing screening. This fee is separate from the blood spot screening. The hospitals in Colorado did not react negatively to the fee because it was such a small amount. With implementation of the bill, CO EHDl is now completely self-sustaining. Brenda asked members if they think NE EHDl should pursue legislation. If EHDl does, we will need support from advisory committee, and help identifying other stakeholders.

Nina Baker asked for clarification regarding who pays the fee. Julie Luedtke said it varies from state to state. Some labs do direct billing, others bill the hospital and the hospital bills the insurance carrier. In Nebraska, the lab bills the hospital and the hospital bills the insurance carrier. The administrative fee comes back to the state, and the funds are used to pay for metabolic formula and foods, and for other administrative fees. Julie L. added that she is not sure what happens when the patient is uninsured. When new disorders were added to the dried blood spot panel, a few hospitals did raise concerns about the fee change from \$45.50 to \$80.50. In the past, when fees had increased, not many hospitals complained. Nina asked if the department of insurance is set up so all Nebraska insurance providers will pay the fee, or will some of that get denied and passed on to the family to pay the fee. Julie L. did not know, but she knows that it is required that all newborn screenings including hearing and heart screenings, and those are covered by insurance, including Medicaid. Krystal added that babies born out of the hospital, the parents are stuck with the bill. The parents are not charged the contracted \$80.50, they are charged whatever the lab charges, which could be a lot of money.

Brenda stated she could draft a business plan for the next meeting, and we could build upon that.

Nina asked how secure EHDl funding is. Brenda stated that at this point, we don't know. We utilize our \$250,000 from HRSA to the fullest. However, CDC is so strict with how funding can be spent, so we are limited on how the funds can be used, which is why we have to request Title V funding. Nina said that in 2019, the Title V needs assessment is starting. She asked if EHDl plans to work with them to address the funding issue. Brenda stated that she works closely with the Title V block grant administrator, and she will be looking into whether or not we can receive more funding consistently. Julie L. added that the newborn screening program relies heavily on Title V funding. Now with the recent fee increase, they rely less on Title V funding which frees up fund to be used elsewhere, so she is encouraging Title V to use those funds toward newborn hearing screening.

The majority of advisory members agreed that it would be appropriate to begin pursuing legislation.

Brenda discussed the CDC funding challenges in greater detail, emphasizing the limitations of how CDC funding can be used. CDC is requesting EHDl Programs collect data from families regarding private early intervention services they receive outside of EDN. CDC is having difficulty collecting the data, so they're putting the responsibility on EHDl programs. Nina stated that EDN already collects data, and asked if EDN could help collect that information. Cole Johnson stated that the survey methodology does not allow for adding unique questions that target various disability types.

Julie L. asked if there is an opportunity for states to provide feedback to CDC about collection of that data, because the collection methods are not standardized across states. Brenda stated that EHDl states all shared that feedback with CDC at the kickoff meeting in 2017, but still continue to request with no specific guidelines.

Brenda shared details of the Audiology Clinic Meeting that EHDl conducted with the five major pediatric audiology facilities in Nebraska. One of the objectives was to discuss the details of the feedback obtained on a clinic survey which was disseminated by NE EHDl in March, 2018. Brenda reviewed the other topics of discussion, and revisions made as a result of the meetings. Brenda emphasized that the EHDl staff has done a lot of work to implement the recommended changes, which included:

- Revising the NE-EHDl Audiologic Screening & Diagnostic Report Form
- Revising the Audiologists page & Families page on the NE-EHDl website
- Developing a NE-EHDl Summary & Reporting Guidelines for Audiologists document
- Starting Sept 2018 - Sending a bi-annual e-mail as a refresher to audiologists regarding reporting procedures to EHDl & ask for program improvement feedback
- Developing a document with a list of birthing facilities who use ABR or OAE for screening
- Offering in service trainings for new audiologists & refresher for experienced audiologists
- Developing a risk factor document & e-mailed document with CDC poster link to birthing facilities
- Mailing risk factor document & CDC poster to primary care physicians
- Developing an Audiology QA report

In the future, EHDl will work towards the following goals:

- Presenting EHDl info to the Audiology Pediatrics class for 2nd year students at UNL
- Searching for webinar training opportunities about EHDl for audiologists, and offer CEUs for the course
- Check to see if NE-EHDl can provide info to ENTs through the Nebraska Medical Association & learn more about the NE Academy of Otolaryngology
- Follow-up on the process to have an audiology class for ENT students' final year of classes

Brenda discussed the various reports that NE-EHDl creates, and how these reports are disseminated. She asked the committee for suggestions on how EHDl can reach out to ENTs and family physicians with this type of data. Kelly R. recommended not reaching to general physicians or family physicians. Based on her experience, her family physician stated that her child was his first patient in 30 years of practice who was identified as deaf/hard of hearing. Brenda added that EHDl met with Mary Pat Moeller, and she shared survey data that showed physicians are comfortable giving results of the hearing evaluations, but not comfortable guiding families through the next steps. Pam Zegers added that for pediatricians and ENTs, their comfort level varies with what they recommend as next steps. She would like to see standardized protocols for all physicians involved in the child's care to follow. In her practice, there are 26 providers, and everyone does things differently. Brenda added that EHDl recently updated the protocols, and received feedback from audiologists that they were very comprehensive. EHDl could create something similar for pediatricians and ENTs to follow. Brenda then asked how that information could be disseminated. Pam added that emails or mailings are not effective. One on one meetings work best. Professionals are busy, so in order to get them to slow down and pay attention, you need to provide something like lunch or snacks. She added that dissemination through the Nebraska Medical Association isn't a good option either, because while many professionals are members, few attend the meetings. EHDl can partner with audiologists to present information at the monthly meetings for continuing education. Brenda agreed that you cannot replace the impact of a face to face meeting, and she will take Pam's suggestions into consideration.

Brenda discussed the HRSA goals, including increasing health professionals' engagement within and knowledge of the EHDl system, improving access to EI services and language acquisition, and improving family engagement, partnership, and leadership within the EHDl programs. Brenda also addressed the current challenges with the HRSA goals, which include assisting families with care coordination plans. This is proving to be a challenge

because HRSA still has not established the specific guidelines. NE-EHDI is continuing to work with the Primary Care Providers & Audiologists to assist families with coordinating care until specific guidelines are established.

Brenda also discussed the success of collaboration with our family support agencies, including our partnership with Hands & Voices/Guide By Your Side Program and HearU Nebraska. Brenda asked the committee for ideas for future family support events, adding that we need to focus on how we can help families with a lower socioeconomic status. The committee did not have any suggestions at the time, but will let Brenda know if they think of anything.

Brenda also highlighted recent discussions with external partners that have occurred since the last meeting. These included:

- Meeting with Mary Pat Moeller at Boys Town - May 2018
- Meeting with Sarah Swanson with Family Care Enhancement Project (FCEP) at the Munroe-Meyer Institute with UNMC - May 2018
- Provided Info about EHDI to Anne Thomas, Coordinator of UNL online Deaf Education Program to share with students - Oct 2018

5. NE-EHDI Learning Communities Update

MeLissa Butler, Community Health Educator Sr. for the NE-EHDI program updated the committee on the Western Nebraska Learning Community. ESU #13 has confirmed that they will be the pilot spoke site. UNL has agreed to be the originating site. NE-EHDI is exploring if we can utilize MCH Title V funds to purchase the tele-audiology equipment. There is a possibility that Title V funds could be used to purchase the equipment. However, Nebraska DHHS is required to determine if the tele-audiology equipment is considered “major medical equipment” or just “medical equipment”. The federal government does not have a definition for major medical equipment so they have put the responsibility back on Nebraska DHHS to define this. Title V funding can't be used if the tele-audiology equipment is defined as “major medical equipment”. So, we are still waiting on approval of funding from the state of Nebraska, and we hope to have a final decision by the end of 2018.

MeLissa also updated the committee on the status of the Hospital Training Learning Community. This is a parent led Learning Community whose purpose is to develop a script and training protocol that helps hospital staff understand the best way to communicate results of the NBHS to families, especially when a baby refers inpatient. This task force kicked off on 12-18-2014, and resumed on 07-24-2017.

The cost to produce the video was funded by Hands & Voices/Guide By Your Side out of funding separate from the family support funding EHDI provides them. MeLissa extended a huge THANK YOU to H&V/GBYS for their support of this project. A draft of the video has been filmed, and we are in the process of gathering feedback. To date, members of the committee were invited to view the video on 09/24/2018. The video was previewed during a presentation at the Nebraska Nurses Association Conference on 10/03/2018. And, the nurses from York hospital were provided a link to the video on 10/19/2018 so they could review it and provide feedback.

MeLissa shared the draft of the video with the committee, and added that since the video is in draft form, it has not been captioned yet. The final video will be captioned in both English & Spanish. After the video presentation, MeLissa shared feedback that has already been collected, including:

- The feel of the video needs to be more natural & warm, possibly have Aaron & Angie sit closer together, and in a more friendly setting like a living room
- Include the Beard kids in a few of the shots to make it more family oriented
- Re-film with the teleprompter closer to the camera, as the talent is looking too far off camera
- Need more emotion shown in facial expressions
- Need to reword GBYS information to clarify that GBYS is part of H&V
- The transitions for scripts need to be slowed down, and need to be consistent with font styles
- A professional needs to deliver the informational piece of the video
 - NE EHDI has hired a professional actor to play the role of “nurse”

Members of the committee shared the following feedback:

- Reword the phrase about the results causing damage to the parent/infant bond
- Use the term “complication” instead of “medical problems”
- Very heavy on script – needs to be lightened up
- Feature more families to show this is a perspective of many parents, and offer other parent perspectives
- Show parents signing with their child
- Show in a setting more open and warm
- State to monitor “typical” development instead of “normal” development
- Verbally say the phrases that are preferred instead of just flashing on the screen
- Have a nurse giving the results to Aaron and Angie
- Laura Beshlar suggested checking with Children’s to see if there is a food space to film on site
- Share importance to follow-up
- Add information about what not to say
- Saying “baby did not pass” can leave a negative impact on families
- Many agree that the verbiage can’t satisfy everyone, but this video is really taking a positive approach to try
- More emotion overall is needed.

Overall, the committee liked the new initial screening and refer cards.

6. NE-EHDI Statistics

Jim Beavers, Business Analyst for the NE-EHDI program presented information on the NE-EHDI 2017 DOB Statistics, as detailed in the handouts.

Jim noted that in 2017 there were fewer births than in 2016. Nebraska continues to stay consistent at 2.1 per thousand identified as deaf/hard of hearing in 2017, which is right in line with the national average of 2-3/1000 identified at birth.

CDC recently posted the national results on their dashboard, and when compared with the Nebraska stats, Jim stated he feels like NE EHDI has improved as much as we can, and we are plateaued at this point. So, our next steps are to begin capturing reasons why babies don’t meet the goal of having a confirmatory diagnosis by 90 days of age. So far, the most common reasons are prematurity, an extended NICU stay, or major medical issue.

Jim also added that he’s working on a Quality Assurance report for the audiology clinics to help them see how their clinic aligns with the national average.

7. 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 H&V/GBYS helps coordinate for families in Nebraska.

Shelli discussed the details of the numbers served as detailed in the handout.

Shelli talked about the family support events that have taken place since the last meeting:

- *Back to School Workshop* 8/4/18
 - This was hosted in collaboration with PTI and Regional Programs for D/HH students. The IFSP Presentation focused on 0-3 year olds, and IEP Preparation focused on 3-21 year olds. Shelli and her daughter Brooke presented on the power of self-advocacy, and a student & parent panel was also presented. Shelli broadcasted the panel via Facebook live. This was a test, because she is trying to find ways to leverage social media in order to reach a wider audience. She added that many families are becoming busier, so she feels the wave of the future is to have information disseminated online rather than hosting in person events.

- Dads Night Out 10/12/18
 - This event was originally scheduled as an outdoor event, but was moved inside due to weather. She was pleased with the event, because the dads who attended talked in greater detail than expected. Her husband Mark and another dad helped to lead the discussion. She added that not having the moms there to do all the talking helped dads to open up. In the future, she hopes to host more events like this one.
- Hands & Voices Fall Family Bash 8/14/18 was postponed due to winter storm. She is planning to reschedule.
- Moms Night Inn 11/3/2018 & 11/04/2018
 - This is an opportunity for moms to share experiences and provide support to each other. Topics included – Self Advocacy, Empowerment, Literacy, Socialization, Communication & more. Seven moms attended and the panel was broadcast on Facebook (FB) live. There have been over 500 views for the panel on Facebook since the event.
- Parent & Extended Family Workshop 11/4/2018 - Cancelled at the event due to ill participants & no shows

Shelli talked about a new program called *Rising Stars* which launched in November 2018. The purpose of the program is to recognize youth up to age 21 who are emerging as D/HH leaders. It will be empowering as well as help promote our youth to become positive role models in the D/HH community. The goal is for kids who are doing great things to be noticed, and to raise awareness that these kids can do anything they put their minds to.

Brooke Janning was the first recipient of the Rising Stars award. Shelli asked the committee to consider nominating D/HH kids they know who would be good candidates for the award. Shelli added that Brooke used to always say she wanted to be a professional soccer player when she grew up. However, her dream has changed, and now she says that she wants to be like Linsay Darnall Jr. and travel all over sharing her story with others. Shelli added that the recognition of the award may have encouraged her to think about pursuing a leadership role in the future.

Ashely Kaufmann asked if the kids come with moms to *Moms Night Inn* (MNI), or if there are other events for kids to attend parents so they can see other kids talk on the panels. Shelli stated that MNI has 3 educational sessions, and the event is just for moms so they can get a break and have a chance to network and learn. Saturday they begin with a nice meal, art activity, and the opportunity to talk about anything and everything. So, that part of the event is limited to moms only. On Sunday there is an opportunity for extended family to come and learn from the panel. Shelli added that she has flyers for upcoming events if anyone is interested in having a supply to give to the families they serve.

Shelli talked about the CMV conference she attended in September, 2018. She stated that she didn't know a lot about CMV prior to attending the conference, but one thing that stood out to her was the fact that, 4 out of 5 babies with CMV will not have health problems, which makes it so difficult to stress the importance. She added that prevention is so simple, and if parents understood it more they would probably be more likely to change behaviors to prevent the spread of it.

Nine states have passed legislation that requires CMV testing at birth. This type of legislation is often passed due to the efforts of passionate parents who speak up to raise awareness.

An average of 25-40% of infected babies will pass the newborn hearing screening.

One argument against CMV screening is that it will cause undue anxiety because most babies will not show symptoms. However, young children who are asymptotic can shed the virus, which can cause problems for an expectant mother if she contracts it from an infected child.

June is CMV awareness month, so Hands and Voices will take an active role in raising awareness during that time.

Based on what she learned, she feels like OB's and pediatricians need more education so they can help families be aware of CMV.

Kristin Jolkowski added that when she was expecting, she asked her OB about CMV, and they didn't think it was a big deal. She added that she feels that the medical community doesn't understand the risks.

MeLissa added that CMV info is included in the packets of info given at hospital site visits and NE-EHDI encourages them to share with their OB partners.

Linsay added that a headline in 2014 stated "wash your hands to prevent your child from becoming deaf." This sensational headline blazed through the deaf and hard of hearing community, because no parent wants their child to be "infected". Linsay added that, while CMV is a big deal, but being deaf isn't. So, when educational efforts are made, we need to make sure to keep those two thoughts separate.

Ashley added that CMV does not just cause hearing loss, it can also cause other neurological issues so our efforts need to address the WHOLE picture with our educational outreach. Shelli agreed, adding that 10-15% of babies born with CMV have neurological issues.

8. EDN Presentation

Julie Doctor from the Nebraska Early Development Network (EDN) presented info on Early Intervention (EI) services in Nebraska. One unique thing about Nebraska is the fact that, per state statute, they operate in the co-lead capacity, unlike any other state. The state is divided into 29 regions, and each region is responsible for promoting EI and other services for families with children who have special health care needs including identifying gaps in services and helping to remove barriers.

Children with conditions like physical, language or cognitive delay, vision or hearing loss, genetic or congenital disorders, sensory impairment, and disorders secondary to exposure to toxic substances including Fetal Alcohol Syndrome can benefit from EDN services. Participation is voluntary, and there are no income guidelines. EDN offers services such as assistive technology devices, audiology and vision services, occupation and physical therapy, services coordination, signed and/or cued language, social emotional supports, special instruction, and speech/language services. Services are to be provided year round, and should be in the home or childcare setting.

Anyone can refer to EDN. Once the referral is made, a services coordinator will make contact with the family within 7 days. The school district is immediately notified if a child has been referred.

Services Coordination is an entitlement for families whose child is identified with a delay or disability. Services Coordination begins at the point of referral. Services are provided up to August 31st of the child's 3rd birthday. After that, a child transitions to Part B which serves children ages 3-21. The services coordinator works to provide a seamless transition for the child, and also works with CPS if the child is in the welfare system.

Cole Johnson talked about two of the main processes of EDN. The first is the Multidisciplinary Evaluation. This is the tool used to evaluate the child and see if he or she meets the state eligibility standards. Nebraska has more strict guidelines than other states, notably that "at risk" youth are not served. Part C considers hearing evaluations as an important developmental domain, because it is key in communication.

The Individualized Family Service Plan (IFSP) is family driven. This plan shows the family what sort of services and supports their child and their family will receive. The IFSP provides support and services in areas like identifying family's concerns/priorities, establishing measurable functional outcomes, coordinating medical/health and education services, identifying the intensity and frequency of services, providing services in the home or community settings & within child/family routines, and providing services year round. Services are reviewed every 6 months, or sooner if necessary.

Cole summarized by stating that high quality early intervention programs for infants and toddlers can reduce the incidence of future problems in their learning, behavior and health status. Identifying infants and toddlers as early as possible will also help to ensure that intervention is provided when the developing brain is most capable of change. Additionally, intervention is likely to be more effective and less costly when provided earlier in life. So, the earlier you start, the better change you have of mitigating problems that would otherwise extend into the school years.

Cole added that recently, research about brain development has become a hot topic. Research has shown that you can make a lot of progress with EI services when the brain is more elastic. So, this is the focal point of EDN, and their agencies are training on the importance of starting EI services when it will have the most impact on the child's development. EI is also less costly than serving a child in SPED throughout their time in school. Cole shared the slide titled *Rates of Return to Hyman Development Investment Across All Ages*. This demonstrates that when EI is started early, your ROI is at the maximum of around \$8, vs. a lower ROI when services are started in school or even post school.

Cole added there is an EDN app, family guide to EI, and a family rights DVD to help guide parents through the advocacy process.

Stacie thanked both Julie D. and Cole for a great presentation, adding that EDN is central to the success of all stakeholders in the room. Stacie asked if the slides could be shared with the committee. Cole agreed to the slides being sent out to the committee. Julie D. added that she has the EDN brochure available for anyone who wants more info to take with them.

Nina Baker stated that even though a referral can be made at any time, it must always be with the family's permission.

Krystal asked for clarification about Nina's previous statement regarding family's permission. Cole clarified that it is best practice, but federal law does not dictate the need for parent consent. However, the initial call is better received if consent for a referral is given by the family ahead of time. Nina added that if a family does not know someone is going to call them, it can create an awkward situation for the Services Coordinator, therefore PTI highly advises to always get consent before making a referral.

Kelly R. stated that her daughter is currently getting EDN services. Her niece also has a physical issue, and is receiving services. She stated that having these services available for both of them has been wonderful, and she thanked EDN for all they do.

Lindsay asked for clarification about sign language services, and wondered if any EDN staff use sign language. Lindsay also wanted to know what percent of those referred to EDN use sign language. Cole stated that there is a mixture of resources. School districts provide services, so they have deaf educators on staff, some who sign and some who provide speech services. The district can either hire someone who signs, or contract the work out. Regarding the percentages referred specifically for sign services, Cole stated that they do not track that type of data.

9. NE-EHDI Program Update and Action Items-continued

Brenda discussed suggestions from previous meetings that NE EDHI plans to pursue in 2019. This will include possibly presenting at the Lincoln Public Schools Special Education Program Meeting, Children's Hospital monthly presentation for specialists, and Complete Children's Health monthly meetings. NE EHDI will also look into publishing an article or advertisement in the Children's Physicians Newsletter, and partnering with ENT/Audiologists to discuss EHDI during Grand Rounds at hospitals like UNMC, Children's and St. Elizabeth. Pam Zegers stated that Bryan does Grand Rounds specifically about pediatrics a few times a year.

NE EHDI will also attempt to contact ENTs suggested by Stacie Ray, and find ways to disseminate information to birthing classes and nurse midwives. Brenda asked if anyone on the committee has other ideas who NE EHDI should share information with. The committee did not have other ideas at this time.

Brenda shared the exhibits and presentations NE EHDI has done since the last meeting:

Exhibits:

- Nebraska Young Child Institute (Kearney June 26 & 27, 2018)
- "What's new in the NICU" Conference - (Nebraska Medicine-Bellevue Aug 23 & 24, 2018)
- March of Dimes Prematurity Summit (Omaha Sept 20, 2018)
- Boys Town Newborn Expo (Omaha Sept 22, 2018)

- NSLHA Conference (Kearney Sept 27 & 28, 2018)
- Nebraska AWHONN Conference (Omaha Sept 27 & 28, 2018)

Presentation:

- Nebraska Nurses Association Conference (Omaha Oct 3, 2018)

Brenda stated that EHDl will be looking for opportunities to exhibit and present at additional events in the future, adding that these are great opportunities to provide information and talk with people face to face. Brenda asked the committee to email her any suggestions they have.

Brenda added that NE EHDl has conducted seven hospital site visits and eight audiology site visits since our last meeting. Objectives of the hospital visits are as follows:

- Meet personnel involved with the hearing screening process
- Learn about their current hearing screening procedures
- Discuss how they educate & communicate results to parents
- Discuss info to determine if steps can be taken for program improvement

Brenda added that many nurses are excited about the guidance available to them in the parent perspective video.

Brenda shared that the following grant reports have been submitted since the last meeting:

- HRSA Annual Financial Report
- HRSA Performance Report
- CDC Annual financial Report
- CDC Evaluation Report

Brenda shared that the EHDl Annual Meeting will be held in Chicago March 3-5, 2019. Per the HRSA grant requirement, EHDl will be sending a parent representative on a scholarship again in 2019. The scholarship will pay for registration and travel expenses. EHDl will be sending out the parent rep application in the near future, with the goal of having the rep selected by the end of November to allow time for the contract process to be completed prior to the meeting. Brenda asked the committee to spread the word about the scholarship, and contact her if they know of a parent who may be interested in attending.

NE EHDl submitted two poster abstracts for the meeting. One is on the Parent Perspectives video, and the other is on collaboration success with H&V/GBYS.

NE EHDl will also be holding a Nebraska state stakeholder meeting at the conference this year, and all attendees with an interest in Nebraska are welcome to attend.

Brenda asked for presentation suggestions for the May, 2019 meeting. Nina suggested having Linsay present information on Junior NAD. Linsay agreed, adding that Junior NAD members will present with him. He will need to figure out the kids' school schedule, and get parental permission for them to attend. Linsay stated that he would like them all to be present so the committee can meet everyone.

Brenda asked for feedback on the meeting space at NET. Everyone agreed that it was a nice meeting space, and they would like to have the meeting there again. Nina added that the sound system is wonderful, and hearing all of the meeting has been so easy.

Brenda announced that the May 9, 2019 will be held at Nebraska Children's Home Society in Omaha, and the November 14, 2019 meeting will be at NET if the room is available. She also stated that she will be sending out a Doodle Poll soon for the spring 2020 meeting date.

Julie L. commended Brenda and the EHDl Team, and commented how impressed she is with the work they are accomplishing with limited resources. Krystal added that Brenda works long hours and works hard. Brenda expressed appreciation for her team, and all the stakeholders.

10. HearU/Hearing Aid Bank Update

Kelly Malcom, UNL Graduate Student and HearU Graduate Assistant, presented the HearU statistics for January 1, 2018 to October 30, 2018, as detailed in the handout.

Nina Baker asked about the data on applications by year, and wanted to know if the child who did not receive hearing aids through HearU due to not being a Nebraska resident was referred to a hearing aid bank in their state. Kelly M. stated that yes, they were referred, and she provided loaners until the child could get other services.

Brenda asked if the new financial criteria has increased administrative time. Kelly M. stated that they had to bring their billing specialist in to help with determining insurance coverage. Stacie added that it has added some time to the application review process because they take special circumstances into consideration, and try to be a little flexible on income guidelines if they're close to being at the lower tier. Stacie added that they will also help families get connected with services they may have not known they qualified for. EDN has helped with covering some of the extra costs of administrative fees.

MeLissa asked if there's a wait list, so those who are denied initially can get hearing aids if there would be extra money at the end of a funding cycle. Stacie stated that they are trying to stick to the criteria to be fair. Laura added that the responsibility would go back to the dispensing audiologist to set up a payment plan.

Additional updates on HearU included:

- HearU's brochure is now available in Spanish.
- HearU website has been redone to make it more user friendly, and members are invited to check it out.

Stacie Ray shared that Kelly Malcom was accepted for an externship at Mayo Clinic in Minnesota. Stacie added that she is really proud of Kelly M., and the externship will be an excellent opportunity for her. The committee congratulated Kelly M. on her accomplishment.

11. Question Prompt List (QPL) for parents to ask audiologist

Jenna Browning, Research Audiologist at Boys Town National Research Hospital presented information of the Question Prompt List (QPL). Jenna is filling in for Merry, who could not at the meeting today. The QPL was developed based on survey results obtained from parents who have a child who is D/HH. This gives parents ideas of what questions they should be asking. The idea is that the families can pick out a few questions ahead of time. This will help push for more family centered care, and allow parents to guide the discussion.

Merry has been sharing the QPL with audiologists and asking how they felt about the questions, and their competency in answering the questions. Merry is also working on a Nebraska Specific resource guide for audiologist to give to families.

Merry recognizes that some may feel concerned, because a QPL like this gives quite a bit of control to the parents, so she was wondering how to get professionals to embrace this and allow parents more of a say in the appointment.

Shelli Janning commented that there are several questions lists in the EHDI Parent Resource Guide (PRG). When a GBYS parent guide goes over the PRG with families, they will pull out the list and help the parents prepare for their next appointment. Nicole Swanson added that the PRG is a good resource, so Merry may want to review a copy of it.

Brenda Coufal asked if it would be helpful to have a separate packet for each of the category questions on the list. That may be one way to make the resource guide less overwhelming for families. Stacie added that as a parent, a list like this would be super overwhelming for a parent of a newly identified child who is likely just trying to figure things out, like how to keep the hearing aids on their child. Jenna agreed that there are parents you wouldn't want to hand this to right away. Kelly Rausch recommended that this should be handed out separately from any other handouts, and at a time after the initial shock of the identification has worn off.

Kristin Jolkowski commented that many of the questions are very device heavy. This may not sit well with many people. Additionally, the Phonak logo should not be on the handout, because it makes the information seem slanted. The handout should only include the Boys Town logo. She suggested that Merry reach out to the regional program coordinators, because they would have information that is less device heavy.

Ashley Kaufman stated that she uses this as a checklist to determine if she has addressed all of these questions with her families. Ashley stated that the family support questions are scariest, because she's not a parent so she doesn't feel like she can authentically answer them. So, to have resources like GBYS available who can talk to families is best. Jenna added that this would be a good resource for students use so they can practice their counseling skills.

Katie added that she likes the idea, because she's a terrible patient and doesn't know what questions to ask at her doctor at appointments. A QPL like this will help patients drive their care.

Linsay stated that he appreciates the list of questions. It reminds him of the resources available in Nebraska. However, he noticed that out of 32 questions, only one addresses sign language. He feels like this is a factual reflection of what is available in our state, emphasizing that Nebraska does not have a single ASL pathway for children who are D/HH. He feels it is important for Nebraska stakeholders to address what is and is not available.

12. Other

Brenda added that Nicole Swanson was accepted for externship at Children's Mercy in Kansas City. The committee congratulated Nicole on her accomplishment.

13. Adjourn

A motion to adjourn the meeting was made by Laura Beshaler and seconded by Kristin Jolkowski. The meeting was adjourned at 3:53pm.

Next Meeting:

- 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