

## The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

November 14, 2019

Meeting Minutes

12:00 pm – 4:00 pm

### NET Nebraska

#### Attending:

#### Members

Nina Baker  
Katie Brennan  
Linsay Darnall Jr.  
Heather Gomes  
Jayden Jensen  
Kristin Jolkowski  
Ashley Kaufma  
Jana Lytle  
Sara Peterson  
Kelly Rausch  
Stacie Ray  
Colleen Richart  
Pam Zegers

#### Guests

Jessica Hoss, GBYS  
Letishia Lindhorst, UNL Grad student

#### Liaisons

Sue Czaplewski  
Cole Johnson

#### Interpreters

Ben Sparks  
Crystal Pierce

#### Staff

Brenda Coufal  
MeLissa Butler  
Jim Beavers  
Jen Lee

#### Newborn Screening Staff

Krystal Baumert  
Julie Luedtke

**Meeting start time** – The meeting was called to order by Committee Chair, Dr. Stacie Ray at 12:03 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.

#### 2. **Review of Agenda, changes**

Katie Brennan asked that if there was time at the end of the meeting, she would like to talk about an upcoming Interprofessional Education Grant. The committee agreed to the added agenda item if time permits.

#### 3. **Review of May 9, 2019 Minutes – Action**

The Meeting Minutes from the May 9, 2019 NE-EHDI Program Advisory Committee meeting were distributed via e-mail before 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 updated the committee on the work that has been done and changes to the program since the May, 2019 Advisory meeting.

Brenda congratulated MeLissa Butler for being a recipient of the 2019 Excellence in Leadership award and thanked all those who provided information for her nomination. Brenda shared her nomination:

*"MeLissa has provided leadership for the NE-EHDI Program as the Community Health Educator/Follow-up Coordinator for over eight years. She is a team player with a strong work ethic, self-driven, reliable, and efficient in*

her work. MeLissa is extremely passionate about helping families determine if their child has a hearing loss in a timely manner so their child can stay on track with their hearing peers to reach their full potential. She is professional and courteous with parents and medical professionals while communicating the importance of the hearing screening process, family support, and early intervention. She has been a super-force for improving NE-EHDI follow-up and reducing lost to follow-up. She led the charge and was persistent to achieve teleaudiology in western Nebraska, which was a huge benefit to children in the area. She led a project to perform a needs assessment on the educational needs of hospital staff regarding the communication of hearing screen results. A training video for hospital staff with the input of many stakeholders was developed. Outside of these major achievements she is always willing to help out the Newborn (bloodspot) screening program when they experience staff shortages, pitching in to enter payments, and updating the newborn screening web page."

Julie Luedtke, Newborn Screening Program Manager congratulated Brenda as well, because she was also a recipient of the 2019 Excellence in Leadership award. Her nomination is as follows:

*"When I review the list of charter traits in the nomination criteria, I absolutely think of Brenda immediately. She has only been the program manager for the EHDI program for just under three years. Within the first six months, she took her team and had everyone engaged, excited, forward-looking, and energized for the next phase of the program. She values communication, both making sure her employees and supervisor are always informed, but always seeking other's opinions, insight, and ideas. Always! She consistently shows her team, her advisory committee, and all the stakeholders she meets from audiologists in private practice to birthing hospital personnel that she genuinely wants their honest input and wants to always work towards improving communication, the EHDI system, and relationships. She came at a time of considerable turmoil when new grant requirements restricted how states can spend their funds, finding creative ways to meet their requirements (in particular, using 25% of the funding for family support) in a way to ensure the goals of the EHDI program could be met and improved upon via contracting with the Hands & Voices Family Support program to assist the program with family outreach to ensure more families were connected with early intervention services. She has also handled very difficult conversations and helped ensure the continued success of the Advisory Committee to respect all viewpoints while being particularly cognizant of the need to minimize or eliminate language that is offensive to people who are deaf or hard of hearing. Because of her strong leadership and team-building skills her team has grown in their skills, their confidence, and their ability to take on more complex projects and situations. I can't think of a more deserving candidate than Brenda Coufal."*

Brenda also congratulated Jen Lee for being accepted for an externship at Yale New Haven Children's Hospital. Her externship will begin in May 2020.

## **5. Advisory Committee Member Roster Updates**

- Johnna Lygrisse – a parent representative has moved out of state
- Joanna Webster - Audiologist with Children's Hospital is a new member

Brenda stated that per the current NE-EHDI Charter "The Advisory Committee shall consist of not more than 20 voting members." Brenda proposed that the Charter be revised to increase the capacity to 30 voting members. This provides the opportunity for the liaisons to be voting members. NE-EHDI also plans to invite Nebraska Association of the Deaf (NeAD) president Mark Anderson, along with more parents.

Linsay asked for a show of hands to see who members are attending the meeting. Members present were: Nina Baker, Katie Brennan, Linsay Darnall Jr., Heather Gomes, Jayden Jensen, Kristin Jolkowski, Ashley Kaufman, Jana Lytle, Sara Peterson, Kelly Rausch, Stacie Ray, Colleen Richart, and Pam Zegers. Members not present were Laura Beshaler, Nancy Hengelfelt, Jessica Larrison, Karen Rolf, Merry Spratford, and Joanna Webster. Katie asked how increasing the number of voting members would impact the committee's ability to meet quorum for each meeting.

Brenda clarified that quorum is half of the voting members, not half of the capacity of the entire charter, so making the change will not impact the committee's ability to meet quorum for each meeting.

A motion to approve the change to the charter was made by Nina Baker, seconded by Linsay Darnall Jr., and unanimously approved by the committee members.

A revised Charter will be posted on the NE-EHDI website.

Linsay asked when the change will be effective. Brenda stated the change is effective immediately.

## **6. NE-EHDI Funding Sources and Goals**

Brenda discussed the NE-EHDI Funding Sources and Goals, as detailed in the Advisory Committee handout packet.

## **7. Sustainability and Legislation Proposal to DHHS Update**

Brenda stated that NE-EHDI submitted a proposal to DHHS in July of 2019 to receive a \$5 administrative fee per infant screened. Brenda, Stacie Ray, and Julie Luedtke met with John Wyvill and Josh Sevier who were both actively involved in passing LB15, which is the bill that adopted the Children's Hearing Aid Act of Nebraska. The legislative bill for NE-EHDI to receive the \$5 administrative fee received internal support from DHHS but did not make the final cut among the bill proposals submitted. After the bill was cut, NE-EHDI received approval from DHHS, Lifespan Health Service Unit Administrator Sara Morgan to utilize HRSA MCH Title V Block Grant funds as needed to ensure the program can continue to operate efficiently and work to improve the lives of families and children who are deaf or hard of hearing in Nebraska.

## **8. HRSA Grant Accomplishments**

Brenda updated the committee on the HRSA Grant accomplishments since the May 2019 meeting. NE-EHDI has continued collaboration efforts for providing family support with the Hands & Voices/Guide by Your Side Program and HearU Nebraska.

Tele-Audiology was implemented in late May 2019 for hearing screenings and diagnostic services. This service benefits families in western NE including the towns of Scottsbluff, Chadron, and Sidney. ESU #16 in North Platte now has a business associates agreement (BAA) for teleaudiology in their area as well.

NE-EHDI collaborated with the Newborn Screening & Genetics Program to develop an educational infographic for Primary Care Providers (PCP). This was sent out to nearly 2,800 PCP's in Nebraska in August 2019.

The HRSA Performance Report and the HRSA Financial Report were both submitted in July 2019.

The Parent Perspective Video was completed in August 2019, and NE-EHDI developed the Newborn Hearing Hospital Champion Campaign. The pilot was launched in November 2019, and feedback so far has been positive. Once the pilot is complete, NE-EHDI will launch the program statewide.

Dr. Heather Gomes, NE-EHDI Chapter Champion gave a brief presentation about EHDI at the Annual Otolaryngology Meeting in October, 2019. Heather highlighted that Nebraska needs to improve the percentage of infants identified as deaf or hard of hearing by three months of age. She encouraged ENTs to make sure that diagnostic evaluations are scheduled as soon as possible on babies that do not pass the newborn hearing screening. The NE-EHDI Team also provided an exhibit display at the meeting.

Dr. Heather Gomes and Dr. Pam Zegers gave a presentation to Complete Children's Health Pediatric Group in October 2019. NE-EHDI intends to continue similar presentations with larger pediatric groups in Lincoln and Omaha

and to offer a recorded version to other practices in central and western Nebraska. NE-EHDI is also looking into offering CMEs for these presentations.

A parent scholarship was awarded for one parent to attend the EHDI Annual Meeting in Kansas City, MO in March 2020. However, since the meeting location is within driving distance from Nebraska, NE-EHDI was able to utilize MCH Title V funding to send three additional parents to the meeting, so four total from Nebraska will attend the EHDI Annual Meeting this year.

Sub-awards are also being processed for the following:

- Roots & Wings - hosted by Boys Town (Feb 29 - Mar 1, 2020)
- Hands & Voices – new sub-award will start 4/1/2020
- HearU – new sub-award will start 4/1/2020

## **9. CDC Grant Accomplishments & Future Work**

NE-EHDI submitted the Year 2 Evaluation Report in September, 2019.

NE-EHDI creates a variety of Data Reports including:

- Annual report for the legislature-(Final report was e-mailed to the NE-EHDI Advisory Committee Members and hard copies are available if interested.
- Data reports are presented at the advisory committee meetings
- Annual Quality Assurance (QA) report for hospitals
- Data is submitted to CDC annually
- Report to D/HH Regional Programs Statewide Stakeholders meetings twice a year
- Annual QA report for main pediatric audiology clinics

Brenda asked if there are other ideas of ways to disseminate EHDI data. The committee did not have other ideas at this time.

Brenda stated that NE-EHDI will continue to disseminate data through various means like meetings and e-mail updates. Additionally, the EHDI Team will present to the UNL Auditory Electrophysiology Class again in March 2020. NE-EHDI will also do another round of meetings with audiologists to look for ways to further program improvement. NE-EHDI plans to send another biannual email to Audiologists who see pediatric patients in December 2019 or January 2020.

## **10. 2019 Exhibits**

NE-EHDI exhibited at the following conferences in 2019:

- Minority Health Conference (York – April 2019)
- Spring Baby Love (Baby Fair) (Omaha – April 2019)
- DHHS Health Fair (Lincoln – September 2019)
- Fall Baby Love (Baby Fair) (Omaha – September 2019)
- March of Dimes Prematurity Summit (Omaha – September 2019)
- Boys Town Newborn Expo (Omaha – October 2019)

- Nebraska Nurses Association Conference (Kearney – October 2019)
- Annual Otolaryngology Meeting (Omaha – October 2019)
- Nebraska Association of Women's Health, Obstetric and Neonatal Nurses Conference (Omaha – October 2019)

Brenda showed a new educational video about newborn hearing screening that NE-EHDI has begun using. Julie Luedtke asked how NE-EHDI will use the video in the future. Brenda said that it's on the NE-EHDI website, and EHDI will show it at future presentations as well. Julie suggested that the video be referenced in parent letters and parent information given at the hospital. Katie Brennan also suggested that EHDI reach out to OB offices to see if they can play it in the reception areas of their office. Jana Lytle asked if the video was in a sharable format so she could share it with Hands & Voices, on grant applications, etc. Brenda stated that the video is sharable on YouTube. Colleen Richart added that the hospital shows videos to new parents, and this would be good to show on the channel that parents watch in the recovery room. Sue said the video is beautiful, but suggested the wording emphasizes language as the priority. Linsay Darnall Jr. stated that he feels the term "birth defect" should be replaced with the term "birth condition". Krystal Baumert suggested having it translated into Spanish and other languages if possible.

## 11. 2019 Presentations

NE-EHDI presented at the following conferences in 2019:

- Sertoma Club (Omaha – January 2019)
- 2 Poster Presentations at EHDI Annual Meeting (Chicago – March 2019)
  - Parents Making a Difference in Improving the NE-EHDI Program
  - Parent Perspectives – A Valuable Part of the EHDI Process
- UNL Auditory Electrophysiology (Lincoln – March 2019)
- NCHAM Coffee Break QI Webinar – PDSA Cycle for the Parent Perspectives Hospital Training Video (June 2019)
- Annual Otolaryngology Meeting (Omaha – Oct 2019)
- Complete Children's Health Pediatric Clinic (Lincoln – Oct 2019)
- Nebraska Speech Language Hearing Association (NSLHA) Conference (Omaha – October 2019)
- Recharge for Resilience Conference (Kearney – October 2019)

Additionally, NE-EHDI has completed eight hospital site visits since May 2019. The goal is to visit all hospitals in the three-year grant cycle. The next grant cycle is four years, so we will make it our goal to visit them every four years going forward. Additionally, smaller birth number hospitals that NE-EHDI would need to travel over two hours one way, will have the option of a virtual meeting rather than an in-person site visit if they have no current issues.

## 12. 2020 EHDI Annual Meeting

MeLissa Butler, Sara Peterson and Hannah Ditmars are collaborating on a poster presentation about Tele-audiology for the 2020 EHDI Annual meeting. They are currently waiting to see if the abstract is accepted.

As previously mentioned, four parent scholarships have been awarded.

Nebraska will host a State Stakeholder Meeting as usual on Monday March 9, 2020.

### **13. Work Starting in 2020**

NE-EHDI will discuss collaboration ideas with the state Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. Brenda hopes to start these conversations in January 2020.

NE-EHDI will check if information about the EHDI program can be included in the Children's Physicians Newsletter, which is sent to all Children's medical clinics every two weeks.

NE-EHDI will look for opportunities to partner with ENTs and/or Audiologists to discuss EHDI during Grand Rounds at Hospitals.

NE-EHDI will look into opportunities to present at the Lincoln Public Schools Special Education Program Meeting which is held twice a year. If possible, would like to present at the spring 2020 meeting.

Brenda asked the committee if there were other ideas on presentations to educate PCPs and ENTs or other collaborations. Katie Brennan suggested reaching out to nurse training programs and medical schools. MeLissa Butler suggested reaching out to the Lincoln Medical Education Partnership, based on a conversation she had with Kristin Jolkowski. Julie Luedtke agreed that this would be a good opportunity. Brenda added that it would be beneficial to see if NE-EHDI could incorporate some information in the curriculum for ENTs in training.

### **14. JCIH 2019 Position Statement**

Brenda reviewed the changes to the 2019 JCIH position statement, which builds upon the 2007 guidelines and the 2013 supplement on early intervention. The new publication has updated best practices through literature reviews and expert consensus opinions on screening; identification; and audiological, medical, and education management of infants, young children, and their families. The updated statement stresses continued surveillance of auditory and speech-language development in all infants, regardless of the outcome of newborn hearing screening.

The position statement suggests that the EHDI programs who meet the 1-3-6 benchmarks should strive to meet a 1-2-3 month timeline.

An endorsement, for well-born infants only, who are screened by automated auditory brainstem response (AABR) and do not pass, that rescreening and passing by otoacoustic emissions (OAE) testing is acceptable, given the very low incidence of auditory neuropathy in this population. Re-screening with OAE after failing an AABR is acceptable with the caveat that a baby with auditory neuropathy in the well-baby nursery will be missed using this screening protocol. However, the JCIH continues to recommend AABR screening and rescreening protocols in the NICU to allow for the detection of auditory neuropathy.

Brenda added that NE-EHDI will continue to encourage OAE only clinics to inform parents that OAE does not rule out Auditory Neuropathy. That way parents have the information they need to decide on their child's hearing evaluation. Julie Luedtke suggested that NE-EHDI develop an infographic for parents about OAE vs. ABR.

Regardless of previous hearing-screening outcomes, all infants with or without risk factors should receive ongoing surveillance of communicative development beginning at 2 months of age during well-child visits in the medical home (AAP Committee, 2017). This recommendation provides an alternative, more inclusive strategy of surveillance of all children within the medical home based on the pediatric periodicity schedule (AAP Committee, 2017). An endorsement of rescreening in the medical home in some circumstances. If the rescreening is performed in the provider's office, the provider is responsible for reporting results to the state EHDI program.

The new statement also recognizes that some families may benefit from infant mental health supports. Infant mental health is a field of research and practice that focuses on optimizing social, emotional, behavioral, and cognitive development of infants in the context of the emerging relationships between parents and infants. The early

identification period of learning, gathering resources and making decisions can be stressful for families. Infant Mental Health specialists and Home Visiting programs may be a useful resource when families are dealing with significant and/or lingering and unresolved life stressors. World Association for Infant Mental Health (<http://waimh.org>) and the HomVEE (<https://homvee.acf.hhs.gov/>) websites provide more information.

Congenital Cytomegalovirus (cCMV) has a larger impact than previously recognized. CMV infection is a leading cause of congenital infection & leading cause of non-genetic unilateral or bilateral sensorineural hearing loss. About 25,000 infants are born each year in the United States with cCMV infection, 10–15% of whom develop sensorineural hearing loss. Children with cCMV can develop late-onset sensorineural hearing loss. JCIH supports urine and saliva swabs for cCMV testing. A standardized, high-throughput test suitable for cCMV newborn screening does not currently exist. A research priority is the antiviral treatment of newborns that have cCMV.

Brenda showed the new CMV parent education video that NE-EHDI developed. Kelly Rausch asked what the target audience for the video was, and suggested that the video be revised so it is geared more toward the general public. She added that it needs more detail about what CMV is, how it's contracted, how to prevent the spread of it, and information needs to be relayed in more layman's terms.

Stacie Ray commented that many of her students are in their mid-twenties, well educated, and of childbearing age. When she asks them if they have ever heard of CMV, the majority do not know what it is. Based on her experience with how few people know about CMV, she feels that we do need to "scare" people a little because it motivates awareness. One hundred percent of the population of childbearing age knows about Zika, and the way many learned about it was through awareness efforts that were a little bit scary. Pam Zegers stated that she prefers we don't scare people, because as a pediatrician she interacts with moms that are already scared. She feels that she and her colleagues need to be better about educating moms, so educational efforts need to be directed more towards practitioners who can, in turn, educate parents. The thing about CMV is that it is not 100% preventable, and contracting it is as easy as catching a cold. Professionals need to educate parents about behaviors that reduce the risk of transmission. Kristin stated she felt that the video would be scary for some moms because there's not a lot they can do, but on the flip side there's not going to be a solution to raising awareness without "hysterical" moms. She felt the video was good and informative, but it could be softened a bit. Kirsten added that she asked her OB about CMV when she was pregnant, and they shrugged it off, but they had Zika posters up throughout the office. Awareness and training need to be put out there because hysteria will move the movement. Jana suggested adding information to the video that shows ways a mother can check to see if she carries the virus, as that might put their mind at ease. Heather Gomes said part of the problem is that it's ubiquitous. Currently, you can't treat it, and more than 90% of the population carries the virus. At Boys Town, they order a CMV swab if deafness is identified early enough. The spread of CMV can be prevented with simple behaviors like hand washing. Kelly Rausch added that she's been on the committee over six years, and she has heard a lot of discussion about CMV but still does not fully understand it. She suggests educating OB's about CMV prevention and testing. Colleen Richart added that she had no clue about CMV until she joined the EHDI Advisory Committee. When first-time moms see the CMV Education video, they might freak out. She didn't recall seeing any information about CMV in the books she read when she was expecting. Colleen agrees that OB's need to be the ones providing this education to parents.

Brenda said that it is important for fellow physicians who are peers of OB's to reach out and help them understand the need for awareness about CMV. Lindsay Darnall Jr. stated he identifies as a Deaf individual. When someone brings up a concern like CMV causing deafness, his reaction is "so what". He lives life as a Deaf person, and it's not that bad. However, when he sees the list of other birth conditions linked to CMV, he sees where the problem lies. As a Deaf person, if he had a child, it would be nice if his child was Deaf like him. But, he realizes that he needs to stop and look at it from the perspective of expectant parents who also want their child to be like them if they are hearing. He added that since EHDI focuses on the newborn hearing screening, are there other groups who oversee

birth conditions who are doing something to increase awareness about CMV? Or is EHDI the only one responsible? He suggested that perhaps EHDI could partner with them to increase awareness. Brenda asked if anyone knows of other programs. Nobody on the committee knew of any other programs that are increasing awareness of CMV. Brenda said EHDI is trying to do our part to raise awareness, but it would be great to partner with others. Nina Baker added that the EHDI Advisory Committee is the only group that she knows of that talks about CMV. She agrees that other areas that oversee other conditions could be good options for a partnership.

Jessica Hoss stated that she agrees with Linsay. As the parent of a deaf child, if being born deaf is the "worst" thing that happens, then it isn't a bad thing. In regards to CMV education, Jessica feels that education needs to happen before people even become of childbearing age. That way you don't get the information about CMV when you're pregnant and now scared to death.

Due to time constraints, Brenda briefly talked about the Deaf Mentor program and stated that she will continue the discussion at the end of the meeting as time permits.

## **15. Tele-Audiology Update**

Sara Peterson, Teacher of the Deaf at ESU #13 updated the committee on teleaudiology in Central and Western NE. To date, they have done four diagnostic ABR's, all in Scottsbluff. Four more are scheduled between now and the end of 2019. None of them are in Scottsbluff so the impact of teleaudiology is spreading to reach other parts of the state. A Business Associates Agreement has been signed with North Platte that includes another ESU 16 office in Ogallala now so they can begin seeing patients. ESU #13 and UNL are also talking about developing a partnership in Valentine before the need arises. So far, feedback from parents has been good, and professionals are on board with getting families connected with the teleaudiology services. They even received a referral from Presbyterian St. Luke's Hospital in Colorado. It's so exciting that now parents don't need to travel eight hours to get the timely audiology services needed for their baby. This effort has closed a gap in western Nebraska.

Jim Beavers asked how parents know about the teleaudiology option. Sara responded that information has been sent out to birth hospitals through pediatric units, but thus far it has been mostly word of mouth advertising. One pediatric provider who had a patient go through the process is now promoting it in their practice. Hannah is working on a pamphlet to increase promotional efforts. To date, they have more patients than anticipated. Sara is currently working on a survey to get feedback from families and providers who have used the service. Julie Luedtke suggested that NE-EHDI send the teleaudiology pamphlet with the EHDI letter to families who might benefit from the service. The committee agreed that this was a good idea.

Sara concluded by saying that she feels there are many good things on the horizon for teleaudiology in Nebraska, and there could be a greater need for services than Sara's time permits.

## **16. Parent Perspectives Video Premiere**

MeLissa Butler, Community Health Educator Sr. for the NE-EHDI program presented the final Parent Perspectives Video to the committee.

MeLissa asked if any of the committee members had comments or feedback on the final video. Colleen Richart stated that while she did grieve and blame herself initially after her daughter did not pass the hearing screening because she was unsure of all of the "what if's" and unanswered questions in her head, but it didn't take her long to move past that. She is proud to have a hard of hearing daughter and doesn't blame herself for anything. She added that she still remembers the first time she met Kelly Rausch, which was on a shuttle bus on the way to the EHDI Annual Meeting, and they connected right away because they had something in common, both of their daughters were named Evelyn, and they've been friends ever since. Kelly agreed, saying that both of their Evelyn's are adorable.

Stacie Ray stated that she is so impressed and proud to be part of this group and the hard work and thought that went into this video. Brenda Coufal added that the advisory members gave a lot of feedback while the video was being produced, so she wanted to acknowledge that the whole committee played a part in making the video a success.

Jessica Hoss added that three of her four children did not pass their newborn hearing screening in the hospital. Each time the results were downplayed by the staff, and she was told it was "probably just fluid". However, because their oldest child is deaf, they did not leave the hospital without an appointment for follow up already scheduled. When their first child referred, they didn't have an appointment set up right away, which led to a delay in the follow-up process, resulting in their son not being identified until nine months of age. She recommended that the EHDI program try to get hospitals to schedule the follow up for each baby who does not pass before they leave the hospital. MeLissa Butler responded that the EHDI program does encourage this as a best practice, but not all hospitals follow that recommendation.

MeLissa added that the Hospital Champion Program will be launched in December 2019, and this video will be shown as part of the process improvement guidelines for hospitals to be recognized as a champion. MeLissa is also working with NET Nebraska to see if the video could be incorporated into a Connect Program about Early Hearing Detection and Intervention in Nebraska.

## **17. NE-EHDI Statistics**

Jim Beavers, Business Analyst for the NE-EHDI program shared that Methodist Women's Hospital is now able to share newborn hearing screening results via HL7 messaging, which consists of a weekly file export that is imported into the Nebraska vital records system. Methodist Women's Hospital is the largest birth hospital in Nebraska, so this is a big step because it saves the hospital time and effort to manually input results.

Jim also informed the committee that Saturday November 16, 2019, the third generation of vital records software will be rolled out. The newest version will be called NX. The advantage of this newest version of the database is that no special software will need to be downloaded to run NX, as it can be completely accessed through the internet.

Jim presented information on the Nebraska vs. National Average 1-3-6 statistics. Julie commented that Nebraska's performance on the 1-3-6 goals is great, but it's taken 19 years to get there. With the new JCIH 1-2-3 goals, it will be interesting to see how realistic it is to achieve those benchmarks. She added that it would be interesting for NCHAM to gather data related to the current state of cases aligning with 1-2-3 to get a baseline. Brenda added that the 1 goal is usually good nationwide, but the 3 & 6 goals are still a struggle for EHDI programs. Kristin asked how EHDI & EDN are communicating with each other. Jim stated that most of the time, the audiologist will refer to EDN at the time of identification. Kristin asked if EDN informs EHDI when they have new identifications. Jim stated that he can access the EDN Connect database to check for referrals. Kristin added that, in regards to the 1-2-3, she knows that it can take up to 45 days for enrollment in EDN services after a referral is made, so that alone will make achieving the 3 goal nearly impossible. That is a federal guideline, so that will be an issue nationwide.

Jim highlighted the reasons for delayed identification, and an analysis of the late-onset cases in 2017-2018, as detailed in the handouts.

## **18. Jr. NAD Presentation**

Linsay Darnall, Jr presented a PowerPoint that was developed by Jr. NAD members.

Jr NAD is a subsidiary of the National Association of the Deaf. It is a youth-based organization designed to teach Deaf youth leadership skills. The organization was founded in 1960, and the first chapter was developed in 1964. Since then, Jr. NAD has spread nationwide. In 1969 the Nebraska School for the Deaf established a chapter that

stayed with the school until it closed in 1998. In 2003, the Metro Regional Programs reestablished the Nebraska chapter. When the chapter reestablished, "Nebowa" was adopted, which allowed Deaf youth in both Nebraska & Iowa to participate. Linsay became involved with Jr. NAD in 2005.

At Jr NAD, they teach three core values: scholarship, leadership, and citizenship. The core value of scholarship is influenced by academics in the Deaf community who have constantly strived to secure and promote good education for Deaf children. Through Jr. NAD, kids are encouraged to prioritize their school work along with the leadership skills they are taught. Leadership is affected by a variety of layers that impact the child's emotional, intellectual, and social skills. Deaf role models are extremely important for developing youth leadership. Role models must possess the ability to influence people and lead themselves. The core value of citizenship is achieved through encouraging Deaf youth to volunteer in their community, in their church, or the Deaf community. Whatever the concept of services is, they develop their pride and identity through service.

Since 2009, Jr NAD had been meeting at a school in Ralston, and later moved to meet at the Nebraska Association of the Deaf. More recently, Jr. NAD reached out to the Omaha Association of the Deaf and negotiated to use the Deaf Club in their facility. Jr. NAD was welcomed with open arms, and it was emphasized the facility belongs to each member of the Deaf community. This feeling of ownership helps the kids know that they always have a place where they can feel safe, be brave enough to stand up and share their energy, ideas, and socialize. The Council Bluffs Silence Club also invited Jr. NAD to use their facility, so they alternate meeting places. The facilities are both Deaf owned.

Opportunities for Deaf youth include learning to run a meeting, brainstorming ideas, and coming up with a plan for events. Deaf youth are also given the opportunity to attend the National Jr. NAD conference. Four members from the Nebowa chapter just attended the national conference in Rochester, New York the previous weekend. There is also the annual Youth Leadership Camp in Stayton, Oregon each year. This is a one-month long camp, and only 64 campers nationwide are selected to attend. The kids leave this camp with new leadership skills they take back home and put into practice right away. The Jr NAD Page Program is another opportunity for Deaf youth who attend the National NAD conference to support the delegates. They also have jobs like introducing speakers, assisting or directing members to correct rooms, workshops, etc.

Jr. NAD members can also gain experience through involvement in activities like fundraising, Midnight Madness, Jr. NAD Prom night, etc. Linsay shared that the Jr. NAD prom night is much like a regular prom, complete with a king and queen, and a variety of other regalia but it's specifically for deaf kids from five different school districts in Lincoln, Omaha, and Council Bluffs. A few years ago, however, the kids decided against prom in favor of a "Midnight Madness" event. To support the event, Linsay had to stay awake all night long, which he didn't like, so he had to say "no more." He has now called in the 20 something graduates of Jr. NAD to support the later night portion of the event so he can go home at 11:00 pm. During Midnight Madness, the kids play games all night and just have fun.

During the NAD National Conference, Jr. NAD members get to sit with the NAD attendees and mingle with the adults. There is also an opportunity for mentorship through the roles the students hold in their chapters. For example, the Jr. NAD Secretary sits with the NAD Secretary, the Jr. NAD Treasurer sits with the NAD Treasurer, Vice President with Vice President, President with President, etc. Each year, there will be a motion that the Jr. NAD president will present to the NAD. Jr. NAD members get the chance to work closely with Deaf adults in their community, so that one day the Jr. NAD President is prepared to take over the NAD President's role.

Linsay added that the Nebowa Chapter of Jr. NAD is unique because there is a mix of modalities including Deaf, hard of hearing, ASL, Oral, and SEE communication approaches. The students are from different schools and states, and this chapter has more advisors than other chapters, with four total along with a variety of deaf adults. The alumnus of Nebowa Jr. NAD includes people who are making an impact on Deaf individuals nationwide.

Jr. NAD teaches Deaf youth to set goals, plan for events, plan for education, plan for their community, and plan for their future. The student's self-esteem skyrockets when they become involved with Jr. NAD. One critical value Jr. NAD teaches is that it's ok to be Deaf or hard of hearing. Deaf individuals are fine, and they can do anything they set out to do. They teach the kids to advocate for themselves, and say "Nothing about us, without us." They encourage kids who are tired of people deciding for them to invite themselves to the table and be included in the discussion. When kids learn to advocate for themselves, their self-esteem shines.

Pam Zegers asked how many students are currently involved in Jr. NAD. Linsay stated that there are currently 22 members. Ashley Kaufman asked the age ranges of the students. Linsay stated they are grades 7-12. Jr. NAD is the prequel to the NeAD youth program. Brenda asked how Jr. NAD gets the word out about the program. Linsay stated that he has been fortunate that, so far "word of hand" has been the best promotion for their program, but they also have a Facebook page where current members can invite their friends to join and keep each other in the loop about events and other things going on. Colleen Richart stated that she had asked if her daughter could attend a Jr. NAD meeting, even though she was only in 6th grade at the time. Evelyn attended and was nervous at first because she didn't know anyone. However, there were some girls she recognized from Metro Regional Program events there which helped break the ice a little. When she got home, she said she wanted to go again. Linsay said that's a pretty common response, and once a student attends, they want to be more involved in the future.

#### **19. EHDl Follow-up & Family Support Events Update**

Jessica Hoss, Parent Guide for Guide By Your Side (GBYS) updated the committee on GBYS's work with EHDl, and the family support events H&V/GBYS helps coordinate for families in Nebraska. Details are included in the meeting handout.

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

Stacie Ray, UNL Professor HearU President, presented the current HearU statistics, as detailed in the meeting handout. Stacie also presented information on how HearU is working with LB15 to serve Nebraska, including what is covered under each tier of HearU's new financial criteria, policies about hearing aid replacement and repairs, and what HearU cannot do.

#### **21. Other**

Katie Brennan, Speech-Language Pathologist at UNL Barkley shared that Ann Thomas and Christy Wisely have received grant funding from the Mid-Plains Professional Upgrade Partnership. The focus of this initiative is to address the critical shortage of highly qualified teachers who serve children and youth with sensory disabilities, including those who are visually impaired or deaf or hard of hearing. This is an extension of the funding they have already received. They plan to begin offering this additional training to a cohort of students in the summer of 2020. Over the five year grant period, three cohorts consisting of 10 students will take field-related coursework. The cohorts will consist of deaf educators and speech-language pathologists, so they are currently recruiting graduate students to participate. The hope is that these professionals will be able to better work together with patients and other professionals when they enter the workforce. This special track is 48 credit hours, and the grant pays for around 38 credit hours under a service agreement that the recipients will serve in the mid-plains area for a designated amount of time.

Brenda Coufal shared more information about the Deaf Mentor program, which is a new grant requirement for the upcoming HRSA grant. NE-EHDl will begin working with external partners to determine the structure of the program and what is best for Nebraska. The grant requires by March 2024, the number of families enrolled in DHH adult-to-family support services (DHH role models or mentors program) by no later than 9 months of age of the child will increase by 10% from the year 1 baseline data. Year 1 baseline data will be collected from April 1, 2020 – March 31, 2021. Brenda stated that she wants to take the needed time to develop a high-quality program, so it may take

the entire four years of this grant to put it together. This is not an expertise area for NE-EHDI, so our external partners will be critical in providing input and structure.

Brenda also informed the committee that she will be on medical leave beginning Monday November 18, 2019, and likely through the end of the year.

## **22. Adjourn**

A motion to adjourn the meeting was made by Kristin Jolkowski and seconded by Sue Czaplewski. The meeting was adjourned at 3:54 pm.

### **Future Meetings:**

- May 14, 2020 - Nebraska Children's Home Society
- October 15, 2020 - NET Nebraska, Lincoln NE

A doodle poll will be sent out in January to select the meeting dates for May & Nov 2021. Save the Date notices will be sent once the meeting dates are set.

Respectfully submitted by MeLissa Butler, Community Health Educator Senior